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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What's Happening to the Health Reform Debate?

In this issue of the Bulletin we have a lot to report about what's happening here and abroad. Bob Brand leads off with what we hope will be an ongoing column providing news from Washington, DC, during this election year and beyond. Donald Light continues his coverage of the health insurance beat, updating the industry’s continuing effort to inoculate itself from risk by excluding sick people and those with special needs from coverage.

We are pleased to have the benefit of Risa Denenberg’s article about lesbian health—a subject long submerged in the provinces of the broader women’s health movement and psychiatry. Denenberg illustrates both the individuality of health needs and the exponential effect that social marginality has on those needs.

From Europe, Hans-Ulrich Deppe describes the tragic dismantling of health care security in what was East Germany and the implications of its conversion to the West German model of “sickness care.” Nancy Oswald introduces another new Bulletin column, “Access to What?” In it, Oswald offers her vision of how health care might begin to address the crisis of need—a crisis also reflected in Joan Minieri’s story about activism and hatred of the homeless.

There’s not much to report about the media-touted nation health care debate—except that it isn’t happening. In March, Health/PAC sponsored a forum entitled “What’s Happened to the Health Reform Debate?” The forum pondered why the Democratic candidates didn’t seem to believe that there was political opportunity in the report that 86 percent of Americans want fundamental changes in the health care system. The health care reform debate has never really been joined by the two primary survivors, Clinton and Brown. Instead, they continue to talk themselves hoarse defending their own and defaming each other’s character.

The 1992 Democratic convention will take place in New York City in mid-July, at which time the city’s transit workers are threatening to strike and disrupt the proceedings. It should come as no surprise that one of their major contract issues is eroding health care benefits. The candidates may come face to face with the health care debate in spite of themselves.

Health/PAC To Study Drug Treatment on Robert Wood Johnson Grant

The Health Policy Advisory Center has received a research grant from the Robert Wood Johnson Foundation beginning July 1, 1992, to study the content of drug treatment in New York City. Emerging out of our Harm Reduction Work Group on health-related issues of drug use, the two-year study is designed to make recommendations for community-driven drug treatment services. It will assess the needs of drug users, the facilities that provide drug treatment services to individuals, the place of addiction and drug use in New York City life, the social and legal context of drug use and treatment, alternative treatment modalities, and the philosophy of drug use and addiction currently driving New York City’s drug treatment services.

In studying the content of drug treatment, Health/PAC plans to continue the multidisciplinary and community-based discussion of drug treatment reflected in recent issues of the Bulletin on “Casualties of War: Fighting the Health Consequences of Drug Policy” (Fall 1990) and “Activism in the New Urban Health Crisis” (Winter 1991). This effort will bring together individuals currently using drugs, individuals in recovery, and ex-addicts; health policy analysts from city and state agencies; and individuals affiliated with the PWA Health Group, Judson Memorial Church, the American Civil Liberties Union, the New School for Social Research, Montefiore Medical Center, and the Community Service Society.
Campaigning for Health

Real Debate on Health Care Reform

by Bob Brand

National health care reform is a "hot" issue in 1992—at least rhetorically. Most of the talk of health care reform is actually about changes in financing, not health care delivery. This country needs to join the two. Financing reform can serve as a vehicle for reforming the health care delivery system only if we build issues of health care and equity into the debate. Creation of a single-payer system of health care financing would offer the American people an opportunity to achieve both types of health care reform.

Meanwhile, the chance for real change in this election year, never great, is fading fast. George Bush red-baits "socialized medicine," while bailing out the insurance industry. The Democrats are, as usual, divided. The Democratic leadership—flush with insurance company contributions and sporting a business-as-usual mentality—have proposed a "play-or-pay" insurance plan combining the worst elements of employment-based care with preservation of the private insurance markets' plundering of the health care system. To top it off, the plan plays right into Republican hands by offering little in the form of cost containment.

Faced with Senators Ted Kennedy and John D. Rockefeller as well as Bush all vigorously defending the insurance industry, Senator Lloyd Bentsen is using his position as chairperson of the Senate Finance Committee involved in health care legislation to say, "Let's do less." Bentsen at least has figured out that the economics of pay or play simply don't work and is unwilling to become the media target of Republican advertising whizzes. He therefore takes the position that all we can achieve in 1992 is legislation to prevent the most blatant forms of arbitrary discrimination against sick people—that is, preventing the most common profiteering practices of the insurance industry.

There may be a meeting of the minds here in that the Bush White Paper on health care reform nearly matches Bentsen's concerns for insurance company reforms. What we find, then, when all the hoopla dies down, is minimal insurance company "reform" legislation and the opportunity to watch each party blame the other for preventing real national health care reform.

Absent from the Debate

The most important issues about health policy in the United States are obviously not being addressed in the current debate. First and foremost, human health is virtually absent from the rhetoric on health care reform. Few in Congress talk about the differential mortality and morbidity that is characteristic of the health care delivery system in the United States. Most do not discuss what it means for 35 million people to have no access to health care insurance and for 50 million others to have limited access. No one mentions issues of class, race or gender, the de facto system of "health apartheid," or the skewed distribution of health care in this country.

Politicians do not talk about the basic systems of health care collapsing at the same time that we are confronting the social epidemics of violence, drug abuse, and the medical epidemics of HIV-infection and tuberculosis. All are given the hands-off treatment by a government singularly dedicated to destroying its own role as a social force for solving human problems. Nor do we hear talk of the impact of our current health care delivery system as the effects of its collapse spread beyond traditionally oppressed populations to more mainstream groups. Even discussion of excess surgery, unnecessary medical and surgical procedures, ineffective medical care, and variations in medical practice are relegated to throw-away lines about developing "guidelines" for medical care.

The initiatives needed to deal with our epidemics and the ways to incorporate the perspectives and energies of activists battling them are totally absent from the debate on health care reform.

The one ray of hope in this dismal debate is the growth of forces advocating a system of single-payer health care in Congress and in more than 20 states. These coalitions directly challenge medical profiteers by seeking to impose a public budgeting discipline on hospitals, health professionals, and pharmaceutical firms.

Increasingly, these single-payer coalitions seek to involve or are influenced by the involvement of health care activists ranging from the Older Women's League to the National Association of Social Workers, Citizen Action, and ACT-UP (AIDS Coalition to Unleash Power). The unions that often form the base of these coalitions include the more progressive and activist unions in the country—American
Federation of State, County and Municipal Employees, the Machinists, the United Automobile Workers, the United Mine Workers, the Amalgamated Clothing and Textile Workers, and the International Ladies Garment Workers, among others. The American Medical Students Association and the Physicians for a National Health Plan are also active participants in many of these coalitions.

The major focus of the health care debate in 1992 will not be the presidential arena, but rather the fight to define health care reform issues in every congressional district in the United States and in the one-third of states electing senators. The role of health care activists and progressives is to define the health care reform issue in terms of human health and in terms of fighting the profiteers who would steal the United States blind while leaving millions and millions of our citizens to suffer from unnecessary disease and disability.

From the clear vantage point of favoring the implementation of a single-payer health care system in the United States, we should continue to critique such ineffectual proposals as the Bush plan and the play-or-pay insurance sector bailouts, while also making clear the limitations and incompleteness of current single-payer proposals. Real reform will come as we advance the struggle for an effective, community-centered, community- and consumer-driven health care system. The health care cost crisis can only be addressed and will only be effectively solved once the health care crisis is joined and resolved in favor of equal access.

During the next year, health care progressives should work in coalitions to advance single-payer national health care reform, challenging congressional representatives to support and campaign for single-payer health care reform in a vocal and popular way. We must also take this opportunity to address issues of differential morbidity and mortality; the need to have a popular and publicly oriented regulation of health empires, health systems, and health providers; the need for systems of reimbursement by outcome measures; the imbalance of specialty and primary care and the consequences of this imbalance for working people, rural areas, and the general care-giving system; and the need to come up with ideas for challenging the control of our health care resources by self-serving, often incompetent, hospital/business trustees.

As the campaign for national health reform heats up in 1993 and 1994, progressives have a unique opportunity to be setting the agenda of what national health care reform will mean. Given the initiatives of trade union leadership, community health care activists, Citizen Action coalitions, and a host of other health forces, we have the opportunity to build an understanding of what health care reform can mean to the people of the United States. Given this understanding, we can build a health care system that is affordable, that promotes both health and economic growth, that, in short, addresses the health care needs of the American people and the struggle to distribute the resources and power inherent in a large health care delivery system in an equitable, democratic way. To do so will take nothing short of a social health movement.

A Plague on Both Their Houses

A special report of Common Cause Magazine, "A Plague on Both Their Houses" (October 1991), asks "Who or what is standing in the way" of health care reform? Vicki Kemper and Viveca Novak provide their own answer: "Few in Washington are willing to blame what may be the biggest culprit of all: the political influence of special interest groups with a vested interest in the status quo. The same insurance companies, doctors, hospitals and drug manufacturers that live off the nearly $700 billion-a-year health care industry are battling comprehensive reform on Capitol Hill and the White House."

They note, "The medical-industrial complex has spawned over 200 political action committees [Health PACs—no relation], which together poured more than $60 million into congressional campaigns over the past decade." Which succinctly explains why the health care reform proposals of the major candidates in this year’s presidential race have spanned the spectrum all the way from modest change to status quo.
Private health insurance is one of the largest institutions in the United States and growing rapidly. At the end of 1988, more than 211 million Americans depended on its protection from serious financial loss in return for $149.4 billion paid in premiums. Slightly more than one-third of this amount went to non-profit Blue Cross/Blue Shield (BC/BS) plans, and slightly less than two-thirds to commercial companies. This total is double that of 1980 ($70 billion), which was in turn more than triple the 1970 figure ($20 billion). Additional premiums paid to self-insured plans and health maintenance organizations (HMOs) come to $73.7 billion in 1988, up from $17.3 billion in 1980, and were too insignificant to measure in 1970.

Through various devices used to avoid insuring high-risk individuals or paying out on claims, the insurance industry has instituted a spiral of exclusion and discrimination, so that those who need coverage most are likely to get the least and pay the most for what they get. Because these practices are inherent in competitive private insurance, it seems that as long as private health insurance companies are permitted to exist, universal health insurance is unlikely to succeed.

Origins of Health Insurance

Health insurance in this country has arisen in three basic ways: (1) people come together to help each other when illness or accident befall them (mutual benefit); (2) the state provides protection in order, among other things, to promote social harmony and a healthy, productive work force (social benefit); and (3) health care providers seek a system to guarantee payment of their bills. The American medical profession quelled attempts at mutual benefit insurance near the turn of the century and blocked the government from providing universal insurance, so that little health insurance existed before the Depression outside of certain company plans in isolated or dangerous industries.

In the late 1920s and particularly in the 1930s, when medical expenses seemed so high, hospitals, medical societies, entrepreneurs, employers, and employee groups invented a wide variety of schemes for paying medical bills. The American Hospital Association set out to find and sponsor a non-competitive, non-profit insurance plan that would cover only hospital expenses, a plan that spread to most states as a multi-hospital prepayment plan called Blue Cross. Thus, American health insurance began as a provider-driven system to get bills paid. Several years later, when the medical profession saw that Blue Cross was working well, it started Blue Shield plans to help patients pay their doctors' bills.

The Blue Cross/Blue Shield plans were predominantly community rated but covered only groups that could pay the premium. Community rating means that everyone in the plan pays the same premium for the same benefits, as opposed to risk rating, in which premiums are based on the health risks of the individual or group. Thus, most Blue Cross plans combined a spirit of mutual benefit insurance for subscribers with professional benefit insurance for health care providers, but they did not address the need for social benefit insurance for the entire population.

The health insurance industry has become a contest to see who can avoid higher risk individuals.

A fundamental change occurred as health insurance spread rapidly. BC/BS plans went from covering 6.0 million people in 1940 to 38.8 million in 1950 and 58.1 million in 1960. Commercial plans grew faster still, from 3.7 million in 1940 to 37.0 million in 1950 to 69.2 million in 1960.

Besides reimbursing hospitals and doctors for what they actually charged rather than offering a limited package of covered services, commercial companies underbid BC/BS plans by focusing on groups of healthy, working people, beginning the erosion of community rating. The market was so large and expanded so rapidly that this erosion proceeded slowly until the 1970s, when the market became relatively saturated. Since then, and with increasing intensity in the 1980s, the health insurance industry has become a contest to see who can avoid higher risk
individuals or insure them without paying out much in claims, creating a spiral of exclusion and discrimination as companies hone their practices finer and finer to exclude ever more people or health conditions. The stakes are high, because only 1 percent of the market (population) generates about 30 percent of all costs, and 5 percent generates about 50 percent. Driving the market is what could be called the Inverse Coverage Law: The more coverage people need (because they are at high risk or sick), the less likely they are to get it and the more they are likely to pay for it.

The Theory of Risk Rating

The object of commercial insurance is to calibrate premiums, exclusions, and other policy features as finely as possible to the risks of its policy holders. Behind this rational economic theory is a theory or vision of the just society, a libertarian ethic that holds it is unjust to force one person to help pay for another person’s needs or welfare. Charity is fine, but taxes or mandatory community-rated insurance are unjust, because they force one person to give up some of his or her freedom to pay for ameliorating the miseries of another.

In contrast, a social ethic would hold that health fundamentally affects the just distribution of opportunities and resources, and therefore equal access to services that minimize the adverse effects of ill health is a prerequisite of the just society. This concept is embodied in the common view of insurance as a system for spreading serious losses over as wide a population as possible. Ironically, however, the concept that “good” and “efficient” insurance calibrates premiums and coverage according to risk factors as accurately as possible leads to no insurance at all, because then there is no risk to be spread around—the fundamental purpose of insurance. And, by creating hierarchies of risk that declare a growing number of conditions as “uninsurable” and limit coverage by risk, private insurance companies are breaking down the social function of health insurance, even for the middle class.

The language of commercial insurance contains two important terms that go along with the notion of risk rating as “good insurance.” The first, “medical underwriting,” refers to practices by which insurers discover risks and illnesses in applicants so that they can avoid covering them, or charge more, or appear to cover them while minimizing the claims paid out. Thus, the industry uses the term underwriting to mean the opposite of its common definition of financial support — a kind of Orwellian doublespeak to obscure that what is really taking place is medical “undermining” through underinsuring. Medical undermining is the central vehicle for carrying out the Inverse Coverage Law.

The second concept is “moral hazard.” This strange term refers to the danger that policy holders may exploit their policy and the insurance company by becoming more careless once covered, either by taking greater risks than they would have before coverage or by defrauding the insurer. Such actions would not only alter the risks being insured but also the losses being claimed. Insurers are quite moralistic about moral hazards; they claim they are perpetrated by manipulators and people of bad character. But while such behavior occurs with a certain frequency, the remedies for moral hazard fall most heavily on those with genuinely serious problems.

Missing from the vocabulary of the insurance industry is a term for a complementary set of actions by insurers who sell policies under false pretenses, deny valid claims, delay payments for months, insert complex provisions that few policy holders understand, charge risk groups much more than their risks warrant, and the like. If insurers face what they call “moral hazard,” then policy holders face what could be called “moral abandonment” by insurers they assume to be honest.

Risk Rating in Practice

How does the insurance industry implement its policy of risk rating which leads to the spiral of exclusion and discrimination? Risk rating as an overt policy comes in several forms. In a recent national survey, commercial insurers said they charge higher premiums for a growing list of conditions, including such common ones as allergies, asthma, back strain, alcohol or drug use, hypertension (even when controlled), arthritis, obesity, and mild psychoneurosis. They write special clauses within policies to exclude coverage for people with cataracts, migraine headaches, back disorders, varicose veins, chronic sinusitis, knee problems, and other disorders (see sidebar). They deny coverage to people with ulcerative colitis, diabetes, cancer, epilepsy, alcohol or drug abuse, severe obesity, and, of course, AIDS. Insurance companies also redline entire industries, such as beauty shops, hotels, restaurants, trucking companies, and even law firms, hospitals, and nursing homes (see sidebar).

One cannot assume that these practices are based on solid empirical and statistical analysis. Groups find that they receive quite different rates from different insurers, a phenomenon that is rarely scrutinized by a regulatory body but which suggests that the actuarial science of risk rating and its application are far from scientific. Aside from the ways in which marketing and profit strategies may affect such premiums, when researchers ask insurance companies to rate the risk of the same cases, they give widely different answers.

Even if one embraces the libertarian ethic of risk rating, evidence indicates that it is not done fairly. For example, the BC/BS plan of New Jersey decided in 1988 to risk rate...
its community-rate pool. It issued page after page of specific weight factors by age, sex, and county of residence; yet it turned out that these weights had no empirical basis. The weights included inexplicable patterns, such as women age 35 being charged 30 percent more than men in one county but being charged no more in another county. Yet no official questioned them, including the professional staff in the Department of Insurance, which approved all of them without exception. Only a suit mounted by a coalition of citizens' groups determined that they were all illegal (see "NJ Citizens Stop Blue Cross Discrimination," Vital Signs, Winter 1990).

Several new practices designed to reduce costs are intensifying risk rating without necessarily being identified as such. In within-group underwriting, insurers are going into small and even middle-sized groups (of up to 100) to risk rate individuals. Up to now, individuals with health problems who were in an existing group were covered once they passed the initial waiting period. However, a group premium can be lowered if exclusion clauses are written for preexisting conditions or if certain people within the group are denied coverage altogether. By 1987, a national survey of mid-size to large employers found that 57 percent used preexisting condition clauses. Insurers use them on nearly all small groups under 50, which make up over 80 percent of all businesses. A 1988 survey of insurers by the U.S. Office of Technology Assessment found that three-quarters of commercial insurers and Blue Cross plans either screen for high-risk members of groups or plan to.

Renewal underwriting is another example of double-speak. Although the term suggests that a policy holder will be financially supported once again, in practice it means that each time the policy is renewed, the insurer goes through the group to identify anyone who has acquired a new risk or medical problem that warrants exclusion or denial. In addition to those denied coverage by this practice, some 10.8 percent of the labor force changes jobs each year and therefore is subject to initial waiting periods that are part of almost all private insurance.

In what can be called policy churning, insurers, their agents, and employers are joining hands to cut costs at the subscribers' expense. While "churning" a stock portfolio generates more commissions, policy churning aims to keep the premiums low by having employers change policies each time the initial waiting period runs out. Waiting periods are a principal reason why first-year premiums are low, because anyone in the group with medical problems gets no coverage for that problem during that time. While originally instituted to reduce "moral hazard," waiting periods combined with policy churning mean that nobody with a medical condition at turnover time ever gets covered. The practice also generates a handsome first-year commission for insurance agents, whose job it is to help employers find the least expensive policy, and the insurer has few claims to pay out. In short, everybody wins except the sick who do not time their medical problems or pregnancies precisely, and the health care providers left with unpaid bills.

| Risk Classification of Health Conditions by Commercial Health Insurers |
|-------------------------|------------------------|----------------------|
| **Higher Premiums**     | **Exclusion Waiver**   | **Denial**           |
| Allergies               | Cataract               | AIDS                 |
| Asthma                  | Gallstones             | Ulcerative colitis   |
| Back strain             | Fibroid tumor (uterus) | Cirrhosis of liver   |
| Hypertension (controlled)| Hernia (hiatal/inguinal)| Diabetes mellitus   |
| Arthritis               | Migraine headaches     | Leukemia             |
| Gout                    | Pelvic inflammatory disease | Schizophrenia     |
| Glaucoma                | Chronic otitis media (recent) | Hypertension (uncontrolled) |
| Obesity                 | Spine/back disorders   | Emphysema            |
| Psychoneurosis (mild)   | Hemorrhoids            | Stroke               |
| Kidney stones           | Knee impairment        | Obesity (severe)     |
| Emphysema (mild - moderate) | Asthma             | Angina (severe)      |
| Alcoholism/drug use     | Allergies              | Coronary artery disease |
| Heart murmur            | Varicose veins         | Epilepsy             |
| Peptic ulcer            | Sinusitis, chronic or severe | Lupus               |
| Colitis                 | Fractures              | Alcoholism/drug use  |

Examples of Industries Deemed Ineligible for Health Insurance Under Selected Commercial Plans

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<td>Amusement parks</td>
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<td>Auto dealers</td>
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<td>Barber and beauty shops</td>
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<td>Car washes</td>
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<td>Commercial fishing</td>
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<td>Construction</td>
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<tr>
<td>Convenience stores</td>
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<tr>
<td>Domestic help</td>
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<td>Entertainment/athletic groups</td>
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<td>Exterminators</td>
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<tr>
<td>Foundries</td>
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<tr>
<td>Grocery stores</td>
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<tr>
<td>Hospitals and nursing homes</td>
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<td>Hotels/motels</td>
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<tr>
<td>Insurance agencies</td>
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<tr>
<td>Janitorial services</td>
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<td>Junkyards/refuse collection</td>
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<td>Law firms</td>
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<td>Liquor stores</td>
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<td>Logging or mining operations</td>
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<td>Roofing companies</td>
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<td>Security guard firms</td>
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<td>Trucking firms</td>
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Source: Promoting Health Insurance in the Workplace: State and Local Initiatives to Increase Private Coverage, Chicago: American Hospital Association, 1988; and interviews with insurance companies.

Genetic and biological research will soon enable insurers to greatly refine and expand risk rating to cover large segments of the population. Genes or genetic markers have already been found for a long list of diseases, and evidence of hereditary patterns has been found in a still longer list. Although the goal of this research is prevention and treatment, its results can be used by insurers and employers to screen out people with risks. Massive screening already takes place for employment and life insurance. Screening to deny health insurance is a natural, if ironic, next step. In addition, the insurance industry is constructing more sophisticated models that combine the weighted product of multiple risks, such as being female and the daughter of a mother who had multiple sclerosis. About 700 insurers share such data through a central data bank known as the Home Office Reference Laboratory.

These activities already are creating a new class of people who are neither sick nor well but “at risk,” which can be seen as “a new medical limbo between health and illness.” Although the scientific probability of an individual’s contracting a given condition may be small and is often the result of interactions with other factors, when in doubt the institutional dynamics of risk rating lead insurers to exclude people with these conditions. Yet recent research shows that even age and sex explain little of the variance in medical expenditures because there is as much variance in expenditures within such groups as between them. Thus, risk rating creates a hierarchy of statuses, albeit biased and inaccurate, from admirable and desired to outcast.

“High risk” and “uninsurability” are not categories in nature but artifacts of the risk-based view of private insurance.

Containing Costs

Besides risk rating, insurers use a number of devices that they claim are cost-containment measures independent of risk rating, since they apply to all holders of a given group policy. These include waiting periods (usually 12 months) during which new enrollees get no coverage for pre-existing conditions; deductibles (usually $500); co-payments (usually 20 or 50 percent) that the policy holder pays of any stipulated bill; and payment caps per treatment, per year, or per lifetime. However, because the impact of these measures is proportional to the medical expenses of subscribers, they are a de facto form of risk rating. These measures can be designed with such a goal in mind, as when inadequate coverage is offered for mental health services or nursing home care.

The growth in these strategies for containing or shifting costs by thinning coverage has been phenomenal. In one of the few longitudinal data sets assembled, Hewitt Associates found that between 1982 and 1987, the percentage of salaried employees in large firms who had to pay a deductible rose from 29 to 65 percent, and the percentage of plans covering all surgery dropped to 15. By 1990, only 5 to 10 percent of all firms did not require employees to pay part of all bills, usually 20 percent up to a ceiling of $1,000 to $2,000.

As means for containing costs, however, these measures do not work very well because patients have little control over costs, particularly for serious problems. The main effect of such strategies is to shift significant amounts of medical expenses back to the individual, so
these practices only "save money" in the sense of reducing the amount of claims paid by the insurer. Deductibles and co-payments reduce minor discretionary visits of the "worried well," but they also reduce preventive visits and early detection of problems. Whether this saves money or not in the long run is a complex question that depends on many factors.\textsuperscript{20} Patients with more serious problems, however, face complex and anxious decisions over which they have little control.

In effect, risk rating is the negative commodification of pain, suffering, and disability.

At the macro level, competitive risk-rated health insurance increases overall costs. First, it simply shifts more of the cost to higher risk groups and individuals. This means that about half the employers in a metropolitan area pay more than the overall average. Second, the additional costs of creating thousands of different policies, marketing them, evaluating bids to choose one, monitoring them, and handling hundreds of different claims forms adds at least 8 percent to everyone’s bill.\textsuperscript{21} Third, insurers create such a bewildering array of policy variations that it becomes very difficult to compare them, even for companies with full-time benefits officers. Finally, the competitive risk-rated market pits one employer against another and thus prevents united efforts to manage health care costs. This causes everyone to be worse off over time as health care expenses continue to rise at about twice the rate of general inflation. Most effective measures, like the total budget caps and fee schedules used by other countries, are not possible unless buyers are united.\textsuperscript{22} Finally, the deregulated market, where true competition cannot often take place, lures fraudulent operators to offer shell policies that in fact pay no claims at all.\textsuperscript{23}

The other reason given by insurance companies for using these measures is to reduce so-called reactive risk—that created by actions of policy holders. Aside from elective visits, however, there is little evidence that reactive risk by patients is a serious reality. While the owner of a building might think, "Now that I have fire insurance, I'll get this building torched," it is difficult to imagine a person saying, "Now that I have health insurance, I'll damage my body and see if I can run up large medical bills." Even acts of neglect, such as not keeping the roof of a building in good repair, do not make sense in health care because the property is the owner's own body and psyche.

The reality of cost containment is that the large number of people with on-going, preexisting medical conditions over which they have no control who are excluded from

\[\Rightarrow\] \textbf{TAKE THE RISK OUT OF RISK RATING}\[\Rightarrow\]

\textbf{RISK ORIFICE MONITORING SYSTEM}

\begin{itemize}
  \item \textbf{WHAT IT DOES:}
  \begin{itemize}
    \item Eliminates guesswork on whether health insurance policy holders actually smoke, drink or use drugs.
    \item Measures a wide range of other risk behaviors, such as sexual activities and caloric intake.
    \item Allows precise calibration of premiums, exclusions, and waiting periods.
  \end{itemize}
  \item \textbf{HOW IT WORKS:}
  \begin{itemize}
    \item Microscopic sensors are placed in the orifices of each policy holder that measure what goes in, when and how much.
    \item Information is transmitted from tiny implanted signal boxes to area information-processing stations.
    \item Can provide continuous or random-time data.
  \end{itemize}
\end{itemize}
coverage during waiting periods is far greater than the number of people who wait to get insurance until they become ill or pregnant. And once insured, people’s ability to shop by price or to decide whether a given additional procedure is necessary or not is very limited. Indeed, no other industrialized nation uses waiting periods, deductibles, or co-payments to any significant degree, and yet all have been much more effective at controlling medical expenditures than the United States.24

Avoiding Payments

The spiral of exclusion begins with de jure risk rating, continues with de facto underinsuring by shifting portions of medical bills back to patients, and ends with strategies to avoid paying claims. The bottom line of many risk-rating and cost-shifting measures is to reduce the number of claims paid. Evidence from the field indicates that insurers, under the pressure of competition and cost containment by employers, are reducing claims in still more underhanded ways.

One method is creating elaborate rules for claims eligibility which, if not followed, disqualify a legitimate medical procedure from coverage. Physicians and patients constantly battle these fine-print provisions, which seem to be appearing with increasing frequency. For example, some policies stipulate that a patient must call a number within 24 hours before an operation to confirm it. Many patients are so anxious and so busy during those 24 hours that making such a call is the last thing on their mind. In one such case, a former student failed to call as she made complex arrangements for her family and job and now faces $11,000 of uncovered bills. Her new policy with this “gotcha” clause had recently been written by her employer with a new insurer to slow the rise of medical costs. Her employer is a hospital.

An increasing number of insurance companies also seem to practice claims harassment, with employers as consenting partners.25 Some companies are known to deny all claims on the first round and then see how many policy holders have the time, organization, and persistence to fight the denial. Making patients responsible for their claims is itself a form of harassment, since it pits the least-skilled, least-experienced party in the health care transaction against the insurance company. Very few other nations involve patients in claims at all. Forms that are difficult to read or understand, requirements that the patient must coordinate a claim with providers, and claims departments with too few telephone lines are other common forms of harassment. All are probably quite effective in both delaying payments so the insurer can gain a few months of additional interest on the funds and reducing the claims finally paid.

A related phenomena might be called exclusion by association. Patients who have exclusion clauses that deny coverage for medical expenses of a chronic condition report that their insurers extend the denial to other medical problems the insurer claims are related. For example, a diabetic with an exclusion clause for her diabetes contracted heart problems. The insurer excluded the medical bills from payment because the heart problems were “associated” with her diabetes. This woman has managed her diabetes for 20 years and thus coped with the exclusion of her diabetes from coverage; but the invocation of “exclusion by association” threatens her ability to afford care for grave health problems beyond her control.

Discrimination

All of these practices systematically discriminate against disadvantaged minorities, older workers, those with chronic conditions, lower income workers, and employees working for small establishments.26 They also discriminate against groups that include individuals defined as high risk, because employers are reluctant to hire them. The trends of unemployment, poverty, and the shift to industries that have poor health insurance all contribute to the spiral of exclusion.

The overall impact of these practices appears to be extensive. As of 1984, about 56 million people, or a quarter of the population under 65, were estimated to have inadequate coverage for major medical expenses.27 A recent study found that 46.8 percent of all unpaid hospital bills in a large Midwest sample came from patients who had health insurance.28 Coverage is probably even thinner for doctors’ bills.

“High risk” and “uninsurability” are not categories in nature but artifacts of the risk-based view of private insurance. In effect, risk rating is the negative commodification of pain, suffering, and disability. It is the process of pricing both the present and future value of illnesses so as to calculate the importance of not selling coverage for them.

Crisis and System Failure

What are the institutional dynamics by which “good” commercial health insurance drives the industry to exclude more and more conditions and claims? The crisis of the capitalist economy29 has prompted employers, as well as the state as the largest insurer of all, to overcome all forms of resistance30 and transform themselves from passive payers to active buyers intent on stopping the fastest-rising cost in their budgets.

For this and other reasons, a growing number of corporations are becoming self-insured, and this has shocked the health insurance industry.31 It has meant a mass exodus of large corporate customers and the reduction of insurers to mere administrators, if anything, of health benefit programs. It put insurers on notice that they would have to work hard for any market share they earned.

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Service institutions, like insurers, now compete to avoid people with unprofitable disorders. Ironically, costs increase. According to Estes and Alford, "State costs are rising both as a result of the costs of competition, privatization and pluralistic financing, and from the additional costs incurred by the state's necessity to subsidize the most difficult (and least profitable) clients who are being dumped on the public sector as too costly for either the nonprofits or for-profits to treat or serve."  

The result is that health insurance companies, as a population or system of organizations, are undermining their own legitimacy by insuring less and less of the population's health risks by acting as "good" insurers are supposed to act. With each passing year, the risk rating and cost shifting intensify. Thus, the appearance of AIDS throws the insurance/delivery system complex into crisis. Raising costs and greater dependence of everyone on insurance intensify the impact of inadequate or no coverage. Medicaid serves as a large catchbasin at the bottom of the health insurance system.

It is increasingly clear that the only viable alternative is national health insurance. However, all the prevailing proposals retain competitive commercial insurance companies. Moreover, none of them address the drive of those companies to avoid high risks and minimize claims payments, even if direct risk rating were prohibited. Only a plan that eliminates the commercial factor has a chance of providing equal access to health care regardless of risk.

11. AIDS and Health Insurance.
13. Ibid.
16. Ibid., p. 62.
27. Farley, op. cit.
28. Saywell et al., op. cit.
Invisible Women
Lesbians and Health Care
RISA DENENBERG

In the 1960s, when women were disclosing the intimate details of their private lives to one another in consciousness-raising groups, a body of knowledge began to emerge about women’s health care experiences. The early women’s health movement, which fought primarily for women’s autonomy in reproduction and in opposition to medical authority, was resisted with all the force that the medical profession could muster. Despite that resistance, the women’s health movement flourished and helped to usher in an era in which women have more knowledge of their bodies and a greater sense of ownership than they did in any previous generation.

As a participant in both the women’s movement and the women’s health movement, I know that many of the leaders were lesbians. During the years of struggling to create an autonomous movement, fighting for abortion rights, looking at our own and each other’s bodies with plastic vaginal speculums, and creating feminist clinics, a mere handful of projects and programs for lesbians were developed. Our issues were subsumed within the more visible agenda for heterosexual women’s rights. The women’s movement both faltered and flourished: it undertook the complex task of broadening to include issues of race and class, and the single-issue battle for abortion rights became a call for prenatal and child care and against sterilization abuse. And in the 1980s, the reality of how women were being affected by AIDS became a consuming item on the women’s agenda. Finally, after years of working on such crucial issues, it is still difficult for lesbians to articulate our own health care needs.

It is an even greater task to get our needs recognized by others, given the widespread view of homosexuality and lesbianism. Heterosexuality is still seen as the universal norm, and the notion persists that homosexuality, and particularly lesbianism, doesn’t matter. In the right-wing, conservative view, homosexuality is sinful, and therefore matters more, but a great many liberals, and even progressives, remain doggedly blind to sexuality. This blindness comes in many forms: keeping gay concerns a low priority in progressive movements, closeting of gay leaders in such groups, and widespread discomfort with public sexuality: “That’s their business, but I just wish they didn’t feel such a need to flaunt it in our faces.” Although the AIDS crisis and the gay response to it has opened the door to overcoming this invisibility and legitimizing the health needs of gay men, the attention it demands has set lesbians even further back from having our health care needs recognized—even when we have AIDS, are dying in astounding numbers from breast cancer and other cancers, and neglect our health care needs in order to care for others. And while AIDS has disproportionately affected gay men, the increase in anti-gay violence that has accompanied the epidemic affects gay men and lesbians equally.

Invisibility and Discrimination
Lesbians are like other women in their vulnerability to illness and to the damaging effect of sexism in the health care system. Lesbians also have unique concerns and experiences that must inform their health care services if individual needs are to be met. A few examples give some hint of the specific problems of discrimination that lesbians face within the health care system:

- Doris entered a therapeutic community to recover from drug and alcohol use, but she found it necessary to hide her gay life-style from the other clients and the staff.
- Evelyn was in therapy for depression for about six months when her female therapist made an overtly homophobic remark. She decided against revealing her growing sexual feelings toward a woman at her job.
- Lori was unable to find a specialist to treat her infertility and assist her with artificial insemination because she is a lesbian.
- Fran came out as a lesbian to her doctor when he was asking her about birth control. During the exam, when he was placing the speculum in her vagina, he was extremely rough, and he used a size that was uncomfortable for her. When Fran complained, he said, “I’m just trying to change your mind.”
- Vivian was committed at age 15 to a psychiatric hospital by her parents when they discovered her having sex with another girl.

Although such invisibility and discrimination are not always life and death matters, they bear upon clinical practice, access to health care services, medical decision making, and the level of discomfort we all feel with wholly depersonalized, even antagonistic health care.
After Sonja’s surgery for breast cancer, her lover Michelle was not allowed into the recovery room. As she sat in the waiting room for three hours, Michelle noticed the nurses escorting other people in to see family members. She was afraid to complain, lest they treat Sonja badly.

Huge gaps exist in the public’s and the medical establishment’s understanding of lesbian culture and lifestyle that make it difficult to confront our invisibility. There is no standard definition of who is a lesbian. Many female couples exist in satisfying, long-term relationships without ever uttering the words lesbian or gay. Other women boldly proclaim a lesbian identity, yet at times have sexual relations with men. Lesbians live in the same unhealthy environments and engage in the same kinds of risky health behaviors as other women—drug and alcohol abuse, eating disorders, smoking, unsafe sex. Yet, lesbians are virtually unstudied as a population by any discipline.

Lesbians exhibit a wide and fluid range of attitudes, behaviors, and self-identities. One common denominator in their relationships, expression of sexuality, lifestyle, and experiences, however, is that they are all outsiders when it comes to getting their health needs met. When lesbians’ health care needs are the same as those of other women for screening, prevention, treatment of illness, education and crisis intervention, lesbians’ needs are less well met than those of heterosexuals. And when lesbians present unique problems and concerns, the medical system generally can’t or won’t meet them. Health care services must be evaluated to determine whether or not they are discriminatory and offensive to lesbians.

Most lesbians have heard of or personally experienced abuses within the health care system because of their sexual preference. These experiences include sexual assault, patronizing treatment, neglect, intimidation, ignorance, and discrimination. Homophobia, in the form of heterosexual presumption, is a common experience shared by all lesbians entering the health system. This is layered on top of the sexism that all women continue to meet in this arena. For lesbians of color, racism within the system adds another layer of discrimination. Poor lesbians, lesbian intravenous drug users, and lesbian mothers all face additional bias.

Lesbians often avoid receiving health care in traditional settings for as long as possible.

The collective experience of lesbians rings an alarm bell of terror for any lesbian entering the system. It is not surprising, then, that lesbians often avoid receiving health care in traditional settings as long as it is possible for them to do so. A variety of other elements and experiences help to determine lesbians’ health status and relationship to the health care system, including their financial standing, work life, sexuality, reproductive life, and support systems.

Money and Work
As women, lesbians earn less money, since, according to the Census Bureau, women’s earnings are only two-
thirds that of men. In addition, lesbians generally have less access than other women to men's resources. Thus, a lesbian household is likely to earn less than a heterosexual household—whether single, coupled, or collective—and is likely to have fewer dollars to spend on health care services. This is compounded by discrimination against lesbians in the work world, which leads to a lack of job mobility. Lesbians may also tend to choose jobs that will not put extra stress on them if their lesbian identity is known. In addition, along with gay men and others in non-traditional families, lesbians usually cannot place a lover or a partner's children on their health insurance policy. Furthermore, lesbians may be less able to recruit support and resources from their family of origin, who often reserve such favors for their married children.

A lesbian household is likely to have fewer dollars to spend on health care services.

The workplace itself places enormous stress upon lesbians. In the work world one often must make the choice between being out, with the accompanying torture of gay baiting and harassment, or remaining in the closet, with the constant fear of exposure.

Although not everyone finds pleasure in tapping into the social network in the workplace, to some extent everyone attempts to ease stress on the job by fitting in and getting along with their co-workers. It is difficult to negotiate the pressures to fit into the social networks that develop among co-workers, and camaraderie creates yet another pressure with negative effects on lesbians who must be closeted in a heterosexual world. Women often invent a "boyfriend," invert pronouns, appear falsely naive about relationships, and stay away from office parties or picnics where a male escort would be expected. For lesbians, work, however satisfying in theory, can be a stress that adversely affects self-image, mental health, household finances, and physical well-being.

Sexuality and Lesbian Relationships

Lesbians often feel isolated, especially when single, and have difficulty finding positive images of lesbian relationships and sexuality. Gay women have similar inhibitions as heterosexual women about approaching, pursuing, and expressing desire to other people. The sexual or romantic isolation that a single lesbian feels may be exacerbated if her friends are competing for lovers within their small circle.

Lesbians are often singled out in medical discussion for the dubious achievement of engaging in low-risk sex. One inaccurate portrayal of lesbian sexuality is that sex is generally chaste, dry, and monogamous. This leads to the idea that lesbians are not at risk of sexually transmitted infections or HIV. It is dangerous to suggest that any category of sex is completely safe from HIV transmission. Furthermore, this stereotype contributes to the myth that lesbians don't have much sex and that this is a frequent cause of failure for lesbian relationships. Lesbian sexuality, like all sexuality, is polymorphous and diverse, and it has never been adequately described in research or literature. But clearly, sexuality is neither the only inspiration, nor the usual cause of failure for female bonding. Gay relationships are generally unsupported by families and communities, are bound by fewer legal ties, and have fewer common children to draw parties together when the relationship feels threatened from within.

Reproductive Health

Lesbians' health needs clearly differ from those of heterosexual women in the area of reproductive health. Lesbians generally have fewer pregnancies in the course of their lifetimes than other women and, hence, longer years of unrelieved menstruation. Anecdotal reports from clinicians providing care to lesbians suggest that lesbians have more complaints about menstruation and fewer about menopause. Women who have sex exclusively with women may have a lower overall incidence of sexually transmitted infections, which translates into a lower incidence of pelvic infections, ectopic pregnancies, and cervical cancer. Women who have never been pregnant have a higher incidence of breast cancer. Thus, there are a few differences that may be based on sexual preference; however, this is not the case in the incidence of most gynecological complaints: fibroid tumors, ovarian cancer, ovarian cysts, endometriosis, cystic breast disease, vaginitis, and urinary tract infections. Yet lesbians receive fewer gynecological services than other women, particularly heterosexually active women who must seek medical care for birth control, treatment of sexually transmitted infections, and pregnancies.

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While a lesbian identity does not preclude sexual activity for money or with men, lesbians often simply deny and ignore needs rather than submit to gynecologists. Often problems such as bad cramps, heavy periods, pain from
endometriosis or fibroid tumors, or severe hot flashes during menopause go untreated. Lesbians skip Pap smears, breast exams, and mammograms, and, in omitting these key health care events, often receive no preventive health care services. Thus, they enter the health care system only during crises.

Lesbians are as likely to want children as other women, but are less likely to act on these desires. External and internalized homophobic messages cast doubt on the appropriateness of raising children for all lesbians and gay men. Both public and private adoption agencies usually bar adoption for gay couples and singles. However, many lesbians are mothers, having born children during prior relationships with men. But many of these lesbians, once out of the marriage and out of the closet, have lost custody of their children.

Mental Health and Emotional Support

In terms of emotional well-being, many gays have experienced early rejection from family, peers, and coworkers because of their sexual orientation. Many young lesbians have been confined in mental hospitals or ordered to therapy by parents for the crime of engaging in same-sex relationships. Lesbians experience the same sexist violence as other women in the form of early sexual abuse, sexual harassment on the job, and rape, and they suffer from the added abuse of homophobic assaults in all forms—comments, threats, beatings, and sexual assault—as well. Lesbians are not exempt from violence within relationships either, but they are less able to seek and receive sensitive support, refuge, and crisis intervention when battering occurs. Several studies show a higher rate of alcoholism and drug abuse among gays.

The gay community offers support to lesbians but may not be a haven. Gay and lesbian community centers—when they exist at all—often have much male and little female leadership and programming. And most towns and cities have no lesbian projects at all—no twelve-step groups, social activities, or educational programs geared for lesbians. Bars are often the only place to connect with lesbians. Rural communities often have informal social networks, but, because they are small, tend to enforce conformity. Such networks also set unrealistic expectations to provide support to group members when illness or crises occur.

Lesbians and AIDS

Lesbians have worked as activists and service workers throughout the AIDS epidemic, yet there is still controversy over whether or not AIDS is a lesbian issue. Lesbians constitute a growing segment of those who are HIV-positive. Lesbians engage in risky behaviors, including sex with those at risk (both men and women) and unsafe use of needles. Lesbian AIDS Project researchers conducted a small study of lesbian intravenous drug users in San Francisco in 1987 and found that many of these women also engaged in other high-risk behaviors such as unprotected sex with men, sex in exchange for money or drugs, and unprotected sex with other women during their periods. Similarly, a study of lesbian sexual behavior conducted by the Kinsey Institute also in 1987 revealed that 45 percent of the 262 self-identified lesbians sampled had been sexually active with men since 1980. Despite this reality, lesbians' risk of disease is overlooked because of dangerous myths about their sexual behavior.

Among groups and organizations doing work on AIDS, research, education, and outreach for lesbians is all but nonexistent. A few projects exist, created by lesbians, that
deal with issues relevant to lesbians with HIV/AIDS, and there are a few support groups for HIV-positive lesbians in some communities. The Lesbians' Educational AIDS Resource Network in Tampa, Florida, has the goal of providing a forum for HIV prevention in the lesbian and female bisexual communities. Groups of lesbians working in AIDS have formed to provide support and activities for lesbians involved in advocacy and service for people with AIDS and also to specifically address lesbian HIV issues.

An important link needs to be made between HIV/AIDS issues and drug use in the lesbian communities. At present, as noted, recovery programs and twelve-step meetings specifically for lesbians are few, but such groups are an important place for lesbians to get help with drinking and drug problems.

Lesbians and Cancer

The health focus for lesbians in the 1990s appears to be cancer. The leadership and involvement of lesbians in the women's cancer movement and its projects has been significant. Composed of networks of local cancer projects, these groups reflect the community's cumulative grief and anger at too many women dying with too little being done in areas of research and meaningful prevention. In 1990, 45,000 women died of breast cancer. At least 10 percent of these were lesbian, probably more, both because the number of lesbians in the general population is usually underestimated, and because of the increased risk of breast cancer in women who have never been pregnant.

Most other cancers and chronic and life-threatening illnesses affect gay and straight women with similar frequency, but they often affect lesbians in a different way than other women. The problems lesbians often confront in dealing with the health care system—lack of health insurance, resources for health care services, and community support, the invisibility of lesbians and hostility towards the ill person's partner—all surface with particular harshness at times of immense crisis—at diagnosis, during treatment, at death. Heartbreaking stories, such as that of Sharon Kowalski (see "The Fragile Rights of Sharon Kowalski," Spring 1989 issue) are commonplace in the lesbian community.

Cancer activism is an integral part of lesbian communities throughout the country. Several projects have formed to deal exclusively with lesbian cancer issues: the Chicago Lesbian Cancer Project, the Women's Cancer Resource Center in Oakland, California, and the Mary-Helen Mautner Project for Lesbians with Cancer in Washington, DC. Lesbian cancer projects organize support groups and provide services such as transportation, child care, and housekeeping for sick lesbians in addition to outreach, education, and activism. But just as gay men cannot cope with the AIDS epidemic without external supports, lesbians cannot tend to each other adequately without leadership and initiative from the medical community, the government, and the community-based organizations.

Resources

Some resources have already been created to help lesbians deal with their health problems, although these are far too few and limited to meet the existing need. Among the published pamphlets, books, and other literature on lesbian health, the original prototype is the still-in-print Lesbian Health Matters! published and distributed by the Santa Cruz Women's Health Collective. Our Bodies, Ourselves has a chapter about lesbians, and several other books have been published by women's and gay presses (see sidebar).

Some lesbian health projects have been developed over the years by various women's and gay groups. In the 1970s, feminist-run clinics such as the Santa Cruz Women's Health Center, the several Feminist Women's Health Centers, and the Cambridge Women's Health Center commonly set aside certain nights for lesbians. Although these "lesbian nights" smacked of segregation, they allowed an unprecedented level of individual attention to the health and sexuality concerns of gay women. Most of these clinics had a majority of lesbians in leadership roles, who frequently found themselves working on heterosexual issues while complaining about "not getting to our own issues," just as lesbians now debate the virtues of fighting AIDS along with gay men while perpetually relegating lesbian issues to the back burner. Many feminist clinics have foundered altogether in the recent climate.
of cutbacks and anti-abortion activism, and those that continue to function have fewer resources for special programs.

Other projects were developed in the 1980s, including the Lesbian Insemination Project, the Lesbian AIDS Project, the Lesbian Health Information Project in San Francisco, and the Lesbian Illness Support Group in New York.

Less than a handful of lesbian health clinics currently exist. At some, including the Lyon-Martin Clinic in San Francisco and the St. Marks Women’s Clinic in New York City, many straight and bisexual women also receive health care. Others are gay/lesbian clinics, such as the Community Health Project in New York, Fenway Community Health Center in Boston, and Whitman Walker in Washington, DC. Lesbians working in these projects voice concern that gay men have always been better served, and that now AIDS programming has left scant resources to serve gay women, even gay women with AIDS.

New York City has an office on lesbian and gay health concerns that functions as a liaison between the lesbian and gay communities and the health service sector. The emphasis is on providing training and education to health professionals so that they can better serve the gay community. The office also provides technical assistance and support to community organizations and co-sponsored a conference on Lesbians and Life-Altering Illness in Fall 1991.

Research

There is little research on the health of lesbians and even less that would provide evidence of the kinds of changes needed in the health care system to appropriately

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**BOOKS ON LESBIAN HEALTH**


**Artificial Insemination: An Alternative Conception for the Lesbian and Gay Community**, by the Lesbian Health Information Project. Order from San Francisco Women’s Centers, 3548 18th Street, San Francisco, CA 94110.


**Cancer Journals**, by Audre Lorde, Spinsters Ink.


**Lesbian Health Matters!** by Santa Cruz Women’s Health Collective, 1979. Write Santa Cruz Women’s Health Center, 250 Locust Street, Santa Cruz, CA 95060.


address lesbians’ needs within the health care system. One of the few surveys of health care experiences, attitudes, and needs of lesbians was undertaken by Judith Bradford and Caitlin Ryan in 1984 through the National Lesbian and Gay Health Foundation. This ambitious 104-question survey was answered by nearly 2,000 lesbians throughout the United States. Most of the respondents were white, college-educated professionals. Some principal findings from this study include the following:

- Fifty percent of the lesbians surveyed had not had a Pap smear in the previous 12 months, and many of the respondents were not receiving any care for existing gynecological problems.

- The most common health problem reported was depression.

- Most women felt unable to disclose their sexual preference to their usual health care provider—yet 80 percent reported experiencing discrimination based on their sexual identity.

- The most frequently reported concern regarding access to health care services was insufficient money; this was the primary reason cited for not seeking health care.

- Of the women who reported the experience of rape, only one-third had ever sought help.

- Stress-related illnesses, including ulcers, allergies, and hypertension, were common among the lesbians responding.

The authors conclude that the data confirm that lesbians face many obstacles in negotiating the health care system, often do not receive important health care, and have health concerns in a variety of areas. They cite the need for further research and documentation in the areas of “discrimination, physical and sexual abuse,...the need for mental health services and the training of providers; the impact of outness/closetness on mental health, and access to non-discriminatory and informed services.”

Other research into lesbian health needs has also been conducted by the gay and lesbian community. Small-scale, unpublished, and uncompleted research exists and is passed along within small circles of lesbians involved in health politics and clinical practice. Studies of breast cancer, HIV seroprevalence, psychological needs of lesbian couples, attitudes about sexuality, sexual transmission of vaginitis between women, and incidence of environmental illnesses in lesbians all exist in various stages of completion. This type of research is severely underfunded and underreported. Nevertheless, an informal network among lesbian activists, researchers, and clinicians passes along important findings and ideas. Funding and support for this type of work would bring important information into a more public forum.

A Lesbian Health Agenda

Lesbians clearly experience health and illness differently from both gay men and heterosexual women, and their differing needs constitute a lesbian health agenda that must be articulated and made visible. The involvement and action of the health community would hasten the development and enactment of such an agenda. Identifying key issues and appropriate approaches by talking to lesbian leaders is imperative. Health planning agencies need to consult lesbian health experts to determine whether or not services are targeted to, reaching, and acceptable to lesbian clients. Slotting a seat for a lesbian on community advisory boards, medical committees, and planning boards would also be useful.

To begin work on lesbians’ concerns in clinical settings, lesbians might be identified and rendered visible by asking relevant questions and using appropriate language on health forms. For example, terms such as sexual partner or significant other are non-threatening. Heterosexual presumption can be eliminated from history-taking, and lesbian-positive images and literature can be placed along with other educational materials in waiting rooms. Funding is needed immediately for lesbian programming, technical assistance, relevant educational materials, and advocacy. Among the issues on a lesbian health agenda that health professionals need to support are the following items that have already been identified.

Cancer is a serious concern of lesbians, claiming many lives and causing much disability and loss of productivity. Lesbian-informed research will continue to look for earlier detection methods and investigate both environmental and personal risk. Partners and children of lesbians who face serious illness or death need legal protection within the framework of lesbian families and relationships.

Childbearing and parenting is another primary concern for lesbians, whether single or coupled. Few sperm banks are receptive to lesbians, and discrimination hampers many lesbians’ efforts to get pregnant. This often leads to informal insemination with semen from donors who are not screened for HIV and other sexually transmitted diseases. The pervasive discrimination against lesbians in custody proceedings also requires more supportive services and advocacy for lesbian families.

Drug and alcohol abuse is a high-priority issue within the lesbian community that requires research as well as community support. Lesbians and gay men cannot recover from addiction while in the closet and being bombarded with homophobic messages. Lesbians benefit tremendously from participating in lesbian recovery groups, but most communities have none.

Mental health services are a significant need in the gay community. Lesbians seek mental health services most often for depression. There is a growing body of writing and research on battering in lesbian relationships and on the effects of sexual assault and homophobic violence on lesbians. Rejection for early expression of lesbian sexuality and life-style may mark the beginning of a lifetime of alienation from family, teachers, old friends, and coworkers. The closet is a breeding ground for depression, anxiety, and physical complaints as well. Lesbians should be able to choose lesbian therapists, attend lesbian support groups, and be able to identify with a lesbian political action group.

Gynecology represents an area of dissatisfaction for almost all women. Gynecologists are still schooled in sexism. Women report being patronized, misinformed,
lied to, and talked over and about in the third person. They suffer the abuses of unnecessary surgeries, sterilizations, and drug experimentation. Lesbians need lesbian-informed and sensitive obstetric and gynecological services in order to ever consider participating in the basic women's health care services.

Lesbians, like other women, are vulnerable to HIV infection and need to be rendered visible in the AIDS epidemic. A network of services, research, and support needs to be built that includes the lesbian experience of HIV/AIDS.

The time is long overdue for this agenda to be recognized and addressed by the medical community. Lesbians have contributed richly to progressive movements that have brought about changes in the health care system for heterosexual women, for gay men, and for other minority communities. We will continue to do that work, but lesbians' health needs must no longer be left off of the agenda as we fight for the changes that are so sorely needed in the health care system.
German Unification and European Integration

HANS-ULRICH DEPPE

In the Winter 1990 issue of the Bulletin, Health/PAC published a report by Dr. Deppe and Dr. Winfred Beck comparing the health care systems of the two Germanies. In this article, Dr. Deppe extends that analysis to compare these systems with those of other Western European countries and to examine the lessons the absorption of Germany’s socialist system into its capitalist neighbor may have for the integration of the European Community. Readers will note that what we commonly refer to as a health care system and its insurance and institutions is here termed a “sickness” system—a description used by European progressives to indicate that the health care system emphasizes care for people when they are sick rather than preventive care that would help them stay healthy.

Western Europe has been undergoing startling changes in the last few years: the collapse of the socialist countries of Eastern Europe, the integration of the capitalist countries of the European Community, and the unification of the two German states, with their different social systems. The center of Europe is moving, with “Go east” as the new catchword. Beginning in 1993, Western Europe will establish a free market for commodities, labor, services, and capital. These changes will undoubtedly affect health care in all the countries involved. This article will look at the transformation in health care already begun in Germany to see what relevance it may have for the rest of Western Europe.

When analyzing the health care systems of different countries, it is important to understand that they are both the result and precondition of social and political processes and conditions. It is impossible to analyze health care without recognizing that it is an integral part of a society’s overall dynamics, with roots in other social arenas. Although the health care system is a relevant factor, it does not drive social policy, but is itself subject to a variety of social influences, and it is important not to overestimate the role of health policy in social analysis.

With this in mind, there are four questions to consider when analyzing a country’s health care and comparing it to other health care systems: (1) Who pays for health care and what is the cost? (2) Who provides the services and benefits? (3) Who regulates the system and makes the decisions? and (4) Who owns the institutions of health care? To assess the results of German unification on health care in the formerly divided country and its relevance for the other countries of Western Europe, it is first necessary to describe some of the features that were unique to the East and West German systems.

The GDR: Centralized Health Care

In the German Democratic Republic (GDR, or East Germany), the state played a central role in the organization of the health care system. That system excluded private elements and was highly integrated into the social arena. Health was seen as a collective and social good, and the right to health care was written into the constitution of East Germany. All health care institutions were public or state owned. Their organization and regulation were directly integrated in social policy and the economic process. Protection against sickness, age, and disability was guaranteed by one central social insurance system, which was part of the state apparatus. Regulations and decisions were delivered from the top down, like military commands, and mandated by an inflexible state bureaucracy. True democratic structures were weak, even for a socialist democracy, and became more so as economic problems multiplied. Because the individual branches of social security had no autonomy from the state, the GDR’s economic and political crises had an immediate impact on health care.

In the German Democratic Republic, health care was financed by state subsidies and by the fixed low fee charged to individuals for national social insurance. In 1989, government subsidies for health care covered 50 percent of the total expenditures. Health care funds were administered by the trade unions, a practice not confined to socialist countries but also seen in Sweden and Belgium.

Another unique characteristic of East German health care was the entry point of outpatients into the medical system. Ambulatory medicine was organized and centrally administered in public institutions. In 1989, there were 615 polyclinics (major health centers), 1,030 smaller health centers (ambulatorien), 130 outpatient clinics, 1,600 state-owned outpatient clinics run by individual physicians, 550 community nurse stations, and 390 physicians with private outpatient clinics. Of 21,000 outpatient phy-
sicians, 18,000 worked in state-owned polyclinics, outpa-
tient clinics, and outpatient departments. Of outpatient
physicians, 63 percent were women, and the average age
of all outpatient physicians was 48. In addition, factory
polyclinics provided workers, their families, and those
living near the factory with preventive medicine and
health care.

The structure of health care in East Germany differed
fundamentally from that of West Germany, where outpa-
tient medicine has been a state-controlled field of private
medical doctors. In fact, the GDR system was closer to the
national health systems of Western Europe than to the
sickness insurance system of West Germany. However, its
strong centralization differentiated it from the national
health services.

The FRG: State-Run Sickness Care

Health care in the Federal Republic of Germany (FRG,
or West Germany), a capitalist country, is decentralized
but federally organized, based on the principles of sub-
sidy and welfare. The system (which now covers the
united country) is financed by social sickness insurance,
which is distributed by self-governing, state-controlled,
non-profit institutions. Despite this state involvement,
there is a strong private sector component in outpatient
and pharmaceutical medicine.

The government does not subsidize sickness insurance;
50 percent of the fees for sickness insurance are paid by
employees, and 50 percent by the employer. Since the end
of the 1970s, private co-payments for drugs, hospital, and
dental care have been on the increase. The FRG has 1,147
regional social insurance organizations, with umbrella
organizations coordinating regional activities. The social
sickness funds are self-managed by representatives elected
by employees and by employers, but their activities are
controlled by the state.

Roughly 90 percent of all West Germans belong to a
social sickness fund. Under this system, patients may
choose their outpatient physicians but do not pay them
directly; the outpatient physicians collect their fees from
the social sickness insurance. Outpatient physicians are
entrepreneurs in privately owned offices, and West Ger-
man general practitioners and specialists typically work
in private offices. Ambulatory and hospital care (90 per-
cent of which is public and non-profit) is strictly divided
by economic interests.

Celebrating the fall of the Berlin Wall at the Brandenberg Gate, November 10, 1989.
In West Germany, private physicians have a legal monopoly on outpatient medicine. This means that health care professionals, who control the distribution of social sickness funds, also have a private interest in the system. In addition, the public health system is poorly developed, and many of its functions have been taken over by private physicians. Compared to other countries, expenditures for health care in West Germany are high. West German physicians have the third highest income in the world, after that of the United States and Japan, but health indicators of infant mortality and life expectancy fall statistically somewhere in the middle range.

Rather than health policy in West Germany, there is sickness policy.

The West German health care system has a number of underlying deficiencies. By definition it is oriented to sickness. Rather than health policy, there is sickness policy, and in practice the main concern is cost reduction. Experts, especially physicians, dominate health care and exert a strong influence in directing and regulating the system. West German medicine has a one-dimensional orientation to physical science and technology. In some fields of health care, especially in central hospitals, there is technological overkill, leading to a strong emphasis on diagnosis while appropriate therapy is neglected. The social relationship between health and sickness is ignored, as are primary health care and the promotion of health.

The various fields of health care are poorly integrated. That is seen most significantly in the division between hospital and outpatient medicine, which has far-reaching economic and medical consequences. Outpatient physicians (general practitioners and specialists) are entrepreneurs who invest capital in their outpatient clinic for profit, and are the main arbiters of the quality and quantity of their services. The benefits they apply for determine their income—in essence, a commercialization of medicine.

Since the end of the 1970s, West Germany has experienced an increase in medical co-payments, with more than 7.3 percent of total expenditures for health care today paid by co-payment. This represents a trend toward the individualization and privatization of health costs.

Under the West German system, the consumption and prices of pharmaceutical products are high.

Care of the elderly is seriously neglected. Nursing care for senior citizens is poorly organized, and there are major problems in the public financing of this care.

German Unification: Conflicts and Problems

On July 2, 1990, the FRG and the GDR joined in an economic, monetary, and social union. Border controls were eliminated, and the Deutsche mark became the currency of the German Democratic Republic. This settled the question of economic hegemony. Eastern Europe, the chief market for the exporting of East German goods, was cut off because those countries could not pay in hard currency, like the mark.

On October 3, 1990, the two German states united, with the five federal states of the German Democratic Republic joining the Federal Republic of Germany. On December 2, 1990, the first common elections were held for a national German government. The question of political power was thus resolved, with West Germany the winner of the struggle between the two political systems. East Germany was integrated into West Germany, and the constitution of the Federal Republic became the constitution of the GDR. The German Democratic Republic ceased to exist. For the first time in history, a former “socialist state” was taken over by and formally integrated into a capitalist country without a war—a bitter blow for those of us who have struggled for many years against the capitalist deformation of health care. But this formal economic and political union did not automatically bring about social integration. It is impossible as yet to identify and analyze precisely all the social consequences of this transformation.

With unification, the structural model of capitalist West German health care became the official basis for, and framework of, East German health care, formerly a service...
of the state. This means that the old structures will be transformed as quickly as possible. As of 1991, a new social sickness insurance system was established, and the old East German social insurance system has been divided into sickness, unemployment, disability, and retirement insurance. A state-controlled, private outpatient physicians' network is being established. The polyclinics can continue to function until 1995, when they will be taken over by private outpatient physicians, communities, or private organizations.

At this point, East German health care is coping with two constraints—the necessity of adapting to the new structure and the pressure for technological modernization—which are creating a number of areas of conflict. First, health care is to be financed solely by the fees paid for sickness insurance and no longer by state subsidies. However, fees are determined by a percentage of income, and if income is low and unemployment is high, then revenues of the social sickness funds will be low.

Second, outpatient medicine is being reorganized to establish a private sector. And, as hospitals and polyclinics are streamlined under a market-oriented economy, unemployment among health professionals will increase. Third, private industry is taking over the functions of standard and occupational medical care, functions formerly assigned to state-owned polyclinics. And last but not least, huge environmental problems will be created by technological modernization: the pollution of the earth, lakes, rivers, the air, and the resulting pollution of the food chain.

Other European Health Systems

All of the capitalist countries of Europe have welfare or social security systems that essentially protect the majority of the populations of these countries against the social risks of sickness, age, disability, and unemployment. Within these there are two fundamental types of health care systems: the national health system and the social sickness insurance funds, and the state exerts major influence over both.

The national health system is part of the state apparatus, and the state has a direct impact on it. The social sickness funds of France, the Netherlands, Belgium, Luxembourg, and Germany enjoy relative autonomy under various forms of self-administration. They are state controlled, but the state has an indirect impact, with much room for private forces in the market to play a role as well. The national health systems may be differentiated according to their forms of centralization or decentralization and by patient participation.

Social sickness insurance has a long tradition. In Germany, the funds were established by Bismarck in 1883. Today there are two types; one, the type existing in the Federal Republic of Germany, offers benefits without direct payment to the physician. The other, as in France, reimburses medical costs paid by the patient.

Most countries in capitalist Europe have some form of national health system. The first such system was the National Health Service of the United Kingdom, founded in 1948 as a result of the Second World War. More recently, national health systems were established along with the hygienic reforms in the Mediterranean countries, beginning in 1978 with Italy. They are less the result of administrative, technocratic, or scientific enterprise than of social and political struggles by working class organizations. Today, of the 322 million inhabitants of the European Community, 181 million are covered by a national health system, and 141 million by a social sickness fund. Private insurance funds play only a minor,
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**Rank Order**


*a. Figures are for 1987 unless otherwise noted. GDR figures are for 1989.*
*b. Percentage of expenditures for health care costs.*
*c. Ratio of physicians' income to average income of work force.*
*d. Average deaths in the first year per 10,000 live births.*
*e. 1979; f. 1980; g. 1981; h. 1982; i. 1984; j. 1985; k. 1986.*
*ND indicates no data.*
supplementary role in sickness insurance in all European countries but the Netherlands, where they are a significant factor. The existence of the national health systems of Western Europe demonstrates that state-owned and regulated health care is compatible with a capitalist social system.

The table classifies the health care systems of Western Europe prior to German unification using various health indicators taken from European Community data. It shows differences between states with a national health system and those with social sickness funds in such indexes of the health care system as expenditures, employment in the medical sector, and physicians’ incomes, and such indicators of health as life expectancy and infant mortality. It demonstrates that the health care systems with the highest expenditures for health care and the highest income of private physicians (such as the Federal Republic of Germany) do not necessarily have the highest life expectancy. The data also show that health care in the GDR was not on a level with that of developing countries, as official pronouncements had it, but was similar to that of other countries of Western Europe.

Effects of European Integration

What will happen in 1993, when the borders of the European Community are opened and a free market is established for commodities, labor, services, and capital? My own research indicates that there will be no structural changes in the health care systems. An indication of this is the European Community’s “Social Charter” of 1989, which appears to be merely a ceremonial declaration. We can expect the pharmaceutical sector to take on a new role, however; there is already a broad debate on licensing, public subsidies for costs, prices, and the like. The integration will also have a direct impact on occupational safety. Exposure limits for toxic substances may be reduced to the lowest common denominator. The European Community’s government in Brussels has already issued a number of occupational safety regulations in the last few years.

All the countries of Western Europe, whether they have a national health system or social sickness insurance, are in a race for the highest rate of direct co-payment. This means that in addition to monthly social security payments, the sick will have to pay directly for their health care. Co-payments have been increasing in all of these countries since the end of the 1970s, with consequences for the individualization and privatization of health costs.

In a parallel process, formerly public health institutions are being privatized. But only profitable medical institutions are being taken over by the private sector—non-profit institutions for the treatment of chronic diseases and psychiatric patients will remain under public ownership. This is a familiar strategy from other economic arenas: Socialize the costs and privatize the profits! At this point, the political negotiations surrounding the integration of the European Community are not likely to result in structural changes in Western European health care, but as the individualization of costs and the privatization of profits proceed, they may reach the point where structural changes must, of necessity, follow.

The governments of the European Community are presently attempting to subject national social and health policy to the international economic pressures of competition. Whether or not this succeeds depends on the potential to resist it within each country. For this reason, changes in health care in the near future will be decided not in Brussels, but by domestic social and political struggles in the individual countries.

The integration of the economically similar countries of the European Community is proceeding slowly and cautiously, while German unification—involving two fundamentally different social systems—is moving extremely quickly. It will not be surprising, therefore, if serious conflicts arise in the process.

German Unification and Europe

German unification demonstrates that a socialist country can be absorbed and integrated into a capitalist country without war. The national health systems of Western Europe have already shown that it is possible for socialist elements to exist in a capitalist system without becoming a serious threat to the accumulation of capital. The traditional problems, conflicts, and inadequacies of West German health care will be marginalized and exported to East Germany.

In the last 30 years, the Federal Republic of Germany developed into a strong European economic power with great political influence. German unification will strengthen this position. It will also influence the establishment of the social sickness fund model as a leading European model of health care. The collapse of the German Democratic Republic’s state health service may be used as an ideological argument against the national health services of Western Europe, as illustrated by the slogan, “More private market, less public influence.” The question that remains to be answered is whether the German model of unification will become the model for the integration of the European Community.
If tomorrow Congress miraculously passed legislation creating national health insurance that provided each and every person in the United States with access to our health care system, would the current health care crisis be solved? No. The problem does not lie solely in how care is paid for and by whom. More fundamentally, our current model of health care delivery is expensive and inappropriate for both those who have insurance and those who do not. We need a new model based on preventive and primary health care services.

The November 1991 special senatorial election in Pennsylvania forced our elected leaders to catch up to reality. They finally heard the message that unless they addressed this crisis, they may lose something very dear to them—their elections. (Whether they feel they must attempt to solve the crisis is not so clear.) To call for something as radical as a national health program a mere few years ago would have been dismissed as "socialistic." Harris Wofford promised to work for just such a program, however, and is now the new U.S. senator from Pennsylvania.

The difference is that we now have a crisis in confidence. The system is perceived as no longer working. It hasn’t worked for poor people for a long time, as evidenced by disease rates twice the national average. A crisis in confidence precedes substantive change. Those of us committed to increasing access to care and improving its quality have an opportunity in this new political climate. We can influence the quickly emerging debate by (1) exposing the flaws of the current structure of health care delivery, and (2) proposing an alternative model of care that will work better for all patients. Conditions are ripe for a paradigm shift, a different way of viewing the world.

Defining the Problem

The current crisis has been defined—by the politicians—as one of financing. It has two acknowledged components. First, health care costs are out of control, now consuming over 12 percent of the nation’s gross national product, and an increasing percentage of individual family budgets. Second, somewhere between 34 and 37 million people in the United States do not have any medical insurance, and thus do not have access to health care except through the emergency rooms of public and other safety-net hospitals. As poor people have never had adequate access, however, the current attention given to their plight unfortunately cannot be credited to compassion. Rather, the complaint is that the cost of their uncompensated care is shifted to payers—the government and insurance companies—and this drives up premiums for everybody.

How problems are defined determines how solutions are crafted. Those who name the issues in a policy debate set the parameters—the bottom lines, the outcomes, even which facts and figures have relevance. The Republican administrations over the past decade have been deft at doing this. The problem was "big government"; thus, the solution was to bolster the market economy.

Nancy Oswald is the legislative director for the Health and Hospitals Corporation (HHC), the municipal hospital system of New York City.
and reduce government responsibility for education, social programs, cities—you name it. Just don’t name the military, because the Republicans successfully defined that as outside the parameters of “big government.”

The Democrats, in response, have acknowledged the shortcomings of the market economy as applied to health care. As Rep. Henry Waxman of California has said, “No one competes for the poor.” However, they seem satisfied to see the issue as a crisis of financing, assuming that the solution lies in government finding the right kind or mix of payers. However, the real cost containment—the engine driving this debate—will not be solved by only changing who pays, but by changing what is paid for.

It is a propitious moment. We have an opportunity to put forth our definition of the problem as not just one of financing, but as one of an appropriate model of health care delivery. Poor people don’t have access because the system isn’t structured to be available to them. It could be argued that the system isn’t structured to be appropriately available to most people in the United States.

The Medical Model

What are the assumptions of the current model? What are the problems with it? How do we best describe them so that we can propose solutions that work? This isn’t a new exercise. Our current health care delivery system is based on the allopathic medical model not because some smart doctors thought it up, but because its proponents won a political debate in the early years of this century against other kinds of physicians and health practitioners. Moreover, they defeated those advocating a public health model, and henceforth banished it to an inferior status. The winners of this debate got the resources—schools, clinics, hospitals. They also won the ideological debate, so that few people in the United States today have any idea that there could even be another approach to health care. What has changed, though, is that most people are no longer satisfied with the current one.

There is a new debate to be won—a new model of health care. Raising consciousness, questioning assumptions and suggesting other models are important political tasks. In this era of sound bites, we have to make our questions simple. So, simply, what is the medical model? It is disease oriented. Patients get attention only when they are sick, rather than learning how to keep themselves from getting sick when they are well. The system focuses on patients’ deficiencies and pathologies, not their resources.

The medical model is provider centered. The operations and the bricks and mortar of health care institutions are designed and implemented around the needs of the institution, not the needs of the patients. Schedules, forms, hours of operation, location and layout are determined by the priorities of those giving the services, not those for whom the services are meant.

The medical model is physician centered. Although the delivery of health care takes many kinds of people—nurses, technicians, midwives, social workers, clerical staff, maintenance staff, administrative staff, and many others—the financing and delivery of care revolves around physicians. And of all these health care providers, physicians are the ones with the most ingrained medical model concepts. All other providers must structure their services around those of the physician.

The medical model is focused on the individual patient. She is seen and treated in isolation from her family, her community, her school, her occupation, her environment. Moreover, the specialty medical model—

Who Wins, Who Loses?

The way we deliver health care is both outrageously expensive and outrageously inappropriate. It costs a lot more to treat a low-birth-weight baby than to provide prenatal care; to treat pneumonia than to take care of a cold; to treat AIDS than to provide resources for education and prevention; to surgically remove a diabetic’s leg rather than to control diet through proper nutrition. So why do we do it this way?

All the financial incentives in the current model reinforce it. Physicians make more money and have more prestige and power than other health care providers. Specially physicians make more money and have more prestige and power than primary care physicians. As there is no public assistance to attend medical school, students pay their own way and graduate with an average debt of over $50,000. Given this, are they more likely to choose a subspecialty that provides a salary of $500,000 a year or to make $80,000 in a primary care field? So, in the United States, 70 percent of the physicians are specialists, and 30 percent go into primary care, as opposed to other industrialized nations where the percentages are approximately reversed. And there are critical shortages of primary care doctors, nurses, midwives...
and health practitioners of every stripe. The specialists have defined the model. It works for them, and they have succeeded in creating public policy that continues to provide resources for that model. But today that model is costing too much, and it is clearly not working very well.

The deficiencies in the system that are becoming obvious to the majority of people in the United States today have been apparent to poor people for a long time. Poor people have had access to the system mainly as teaching material for specialists in training. In the physician-centered, disease-oriented model, those who don't have access to preventive and primary care may receive the most expensive high-tech and specialized care. Our teaching hospitals will admit a homeless man into an intensive care unit at hundreds of dollars a day, save his life, and then turn him back into the streets until he is sick enough to return.

No system can provide everything for everybody. It's a question of priorities and what criteria are used to set them. The issue isn't whether health care is rationed, but how. Our current health care delivery system rations health care, and especially primary health care. We just don't call it that. The term has been kept on the margins of the debate, unless the Canadian system is being described. The Oregon proposal to ration health care services (see "Oregon Redux," Vital Signs, Spring 1991) does not challenge or change the current rationing based on income and insurance status. It would systematically ration care only for Medicaid patients.

The rural poor, who live in areas with few physicians of any kind, lack access to health care even in the role of training material. Thus, these areas, with the help of the dominantly rural U.S. Senate, have been given preference in the past decade to the small pot of federal dollars for primary health care for the poor. These funds, mainly in the form of appropriations for community health centers, have withstood the Republican onslaught.

What Works

Community health centers, the institutional embodiment of more appropriate community-based, community-oriented primary care, began as a revolutionary idea in the era of the Great Society. The model was politically acceptable only to the extent that it limited itself to a means of delivery to the poor and did not challenge the dominant medical model as an alternative for the health care delivery system. It survived the Nixon administration, attempts by urban hospitals to hone in on its funding, and the virtual decimation of the National Health Service Corps, on which the centers relied for physicians, during the Reagan administration. This model has become the federal model for primary care to the poor, and now is championed by Republican and Democratic senators alike as the foundation for increasing access. As a model, it has passed significant political tests, and at its best does offer an alternative to the medical model.

A cornerstone of the community health center model is that 51 percent of its governing board must be patients. This immediately sets up a different paradigm than that of the medical model. The message is that patients, not providers, control the destiny of this clinic. The issue at the moment is not whether community health centers perfectly serve the health care needs of their patients. The issue is whether different assumptions about what health care is and who it serves make a difference in how it gets delivered. Do patients served by community health centers have more access to preventive and primary care? Do they get more comprehensive care? Do they make less use of inappropriate emergency rooms? Are family, community, occupation, and environment considered in their treatment? And, most important, is the overall health status of the community served by the clinic improved? The answer seems to be overwhelmingly yes. As Lisbeth Schorr pointed out in her book, Within Our Reach: Breaking the Cycle of Disadvantage, we know the model works; we just don't have the political will to make it happen (see Lisbeth Schorr, "Successful Strategies: Meeting the Needs of Children in Adversity," Fall 1991).

The Great Debate

People without access to health care are poor people—either the working poor without medical insurance or the Medicaid population, albeit with insurance, but so underinsured that either physicians won't see them or won't be paid adequately, if they do. People without adequate access to care drive up the costs of health care. Getting them access to appropriate care, then, is at the heart of the "great health care debate" as the New York Times recently called it. Key to the direction
that this debate will take, though, is the question of access and cost to middle-class voters—many without decent primary care and with expensive specialty medical bills and facing the prospect of huge nursing home bills for themselves or their parents. Unlike 20 years ago, the middle class today does not believe that the health care system is working for them either.

Let us seize this opportunity to frame the issues in the great debate. Let us say loud and clear that the current reimbursement system needs to change radically to encourage primary care, not specialty care. And it should be public policy, not medical school policy, that determines what kinds of doctors are produced. The government has a right and a responsibility to intervene. Let us challenge the assumptions of the medical model that sees people as nothing more than the sum of our organ systems and that makes us dependent on those who see us that way.

The medical profession and the insurance companies created this model and continue to benefit from it. How do we effectively challenge their megapower? In the spirit of the community-based model, let us build a coalition of all those who do not benefit from the current system, who in fact suffer because of it in one way or another—the poor, the elderly, children, women, people of color, inner cities, rural areas, public health professionals, public hospitals, community health centers, primary care physicians, health care unions and more. Let us go on to form alliances with business and middle-class voters who are paying for this irrational and expensive model.

Let us pull together a unified core of our various agendas. It’s time for a paradigm shift in the health care delivery system. Let us build upon the models that we know work—focusing on prevention, primary care, community, empowering patients by building on the resources they have and making them partners in their care, and respecting the contributions of all different health care professionals and their interdependence. Let us create the political will to build the kind of system we want to have access to.

Voices

The Politics of Homelessness: Organizing During a Backlash

by Joan Minieri

T
he nation’s image of President George Bush during a moment of national upheaval is often a picture of him at home in Kennebunkport, Maine: speedboating through the start of the Gulf War, teeing-off and turning to chat with reporters in support of Clarence Thomas before hopping into his golf cart. We see him jogging and fishing, safe, relaxed, and confident.

But the picture of home for hundreds of thousands of Americans has nothing to do with speedboats and golf courses. Estimates of the numbers of Americans who currently live without a permanent home range from 250,000 to up to 3 million. According to the National Coalition for the Homeless, at least a quarter of the homeless population is composed of children under the age of 6. Home is anything but safe and secure: a corner of a cramped room that changes regularly, a brown box in a doorway, the edge of a bench or a cot on a vast armory drill floor surrounded by violence and disease.

In the daily struggle to survive, people who are homeless experience their basic human dignity being constantly eroded. Given the current economic climate, almost anyone is potentially homeless, but most homeless people have grown up in poverty, lacking opportunity, and have become adults with few marketable skills and dangerously low self-esteem.

Homelessness is also a health issue; drugs and disease are endemic. Those whose homelessness was caused to some degree by drugs have limited access to proper treatment.

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Homeless woman in barracks-style shelter in New York City.

ment, and those who are not on drugs when they become homeless become dangerously prone to start on the streets or in shelters. Diseases like tuberculosis, AIDS, and syphilis prey on homeless people, who lack basic medical care and live exposed and unprotected.

In 1981, according to the National Low-Income Housing Coalition, the total federal budget authority for low-income housing was $32.2 billion. For 1992, the total is $9.8 billion. The result of this steady drop in federal support since the Reagan administration has been an entire generation raised with no positive experience of community, without adequate education or health care, amid violence and addiction. Homelessness is an expensive issue; the financial and social costs are staggering, and they frighten off most politicians. To replace the units of low-income housing lost over the past ten years would require over $20 billion, and this would simply arrest the problem. Just as critical is that the steady rise in numbers of people living doubled-up, in public places, and in shelters profoundly affects social relationships and communities and increasingly limits individuals' access to jobs, education, health care, and personal stability.

But listening to the platforms of this year's presidential contenders, one would think that the major housing issue in this country is enabling middle-class people to buy a first home. Homelessness appears as a minor issue, occasionally tucked into a plan for domestic policy, but not a priority and never the source of serious debate. Homeless people are not politically influential. They are poor people, predominantly people of color or physically or mentally handicapped. Their situation is perhaps the most devastating embodiment of racism and poverty.

I have been drawn to respond to these issues for the past six years, working to organize actions and advocate for changes in policy and public attitude. In these times of social and political confusion and frustration, working with people who are homeless is particularly difficult. Recent demonstrations and actions organized by coalitions of homeless people and advocacy organizations have highlighted some of the problems I have observed.

Bringing Homelessness Home

To bring the issues of homelessness straight to the president in a public way, homeless people and their advocates from communities throughout the United States paid a visit to George Bush's home in Kennebunkport, on October 5, 1991. The demonstration was sponsored by Housing Now!, a national coalition formed in 1989 to organize direct actions around low-income housing issues.

It's hard not to feel snubbed by Kennebunkport. It is a physically perfect place, and there are virtually no people walking around to mess it up. Through the downtown, relentlessly upscale and eerily quiet, past the vast, simple homes, well groomed and still, and along the gorgeous, empty shoreline strode 3,000 housing activists from places like Green Bay, Cincinnati, Los Angeles, New York, and Boston. The rally site at Walker's Point was directly across the inlet from the Walker Bush home, and our chants echoed across the water: “Bush, we're coming!” and “What do we want? Housing! When do we want it? Now!”

It would be easy to feel good about rallying in solidarity with the poor in a place like Kennebunkport and to say that something significant had been accomplished. But the complex reality is that while advocating for those who are homeless has always been difficult, the economic hardships of people in the middle class have created a clear political opportunity that is too seductive for elected officials to ignore. And for these politicians, the financial and social demands of dealing with the lack of low-income housing, the effects of addiction, poor health, and personal oppression of homeless people are easier to dodge than to grapple with on a public stage.

There was little official response to the rally in Kennebunkport. The Housing Now! march came a few weeks after a Labor Day demonstration in Kennebunkport organized by ACT-UP, the AIDS Coalition to Unleash Power. The president expressed his outrage at this unseemly visit to his ancestral home and spoke to some extent to the issues raised by ACT-UP. But he did not respond to Housing Now! He didn't need to. Our action was relatively small and our base of support narrow.

Organizing

For me, Kennebunkport also marked the culmination of a frustrating process: attempting to organize a national event in coalition with local groups that are more overextended than ever before, amidst a sweeping backlash against homeless people. I went to Kennebunkport
with the perspective of six years of activism around housing issues in New York City and two years of organizing with Housing Now! Many of the problems we faced in organizing the Kennebunkport demonstration were there from Housing Now!’s beginning, while others resulted from changing times and changing attitudes toward homeless people.

Housing Now! first emerged out of a gathering of 200 homeless people and activists in Atlanta in the winter of 1989, sponsored by Mitch Snyder and the Community for Creative Non-Violence (CCNV), the immense shelter he developed and ran in Washington, DC. Snyder had achieved a certain authority and notoriety for his 51-day hunger strike in 1984, which forced then President Reagan to provide $6 million for the development of CCNV into a model shelter. CCNV invited organizations from all over the country to develop a national strategy for acting together. Groups present at the meeting included the National Union of the Homeless, advocacy and lobbying groups such as the National Low-Income Housing Coalition and the Coalition for the Homeless, as well as dozens of local grassroots organizations.

Over the next year, Mitch Snyder and CCNV were the major force behind Housing Now! and national mobilizing for housing. Snyder’s idea was to bring no less than one million people to a national housing demonstration in Washington, DC, within a year from the meeting. The simple demand was a commitment of $25 billion for affordable housing. This was the total amount cut from the federal budget by the Reagan administration as of 1989.

It felt appropriate to me to work on building a broad base of national support for affordable housing, but I never felt quite comfortable with the organizing process in the Housing Now! coalition. Up to that point, my efforts had been focused on bringing people into the housing movement through activities such as volunteer construction work with squatters in New York City and organizing direct actions to pressure and eventually oust then Mayor Koch. I was working with a cohesive group around a clear target, with an emphasis on reflection and careful planning throughout the process. Now, as I sat in planning meetings in Washington and New York, I got the sense that many of those involved believed that because we were right, we could immediately translate an idea like “one million people” into reality.

For example, although there had been some organized outreach and preparation, Housing Now! did not raise enough money to support a full budget for the New Exodus march of homeless people from New York to Washington that was scheduled to arrive in time for the national demonstration. There were no clear plans to deal with the fact that many of the marchers would have problems with drugs and illness and that they were likely to come with an extremely negative experience of communal living. Four hundred people, mainly from New York City’s streets and shelters, eventually joined this three-week journey. By all accounts, the New Exodus march was disorganized and grueling, yet most of those who participated were deeply affected. Despite the chaos, many used the march as an opportunity to get away from drugs, and individuals from the street and shelters were able to emerge as leaders along the way. It was a powerful challenge, and I have great respect for those who went on the march. But the idea was poorly conceived and irresponsibly executed, diluting its potential effects.

The final demonstration in Washington on October 7, 1989, drew about 100,000 people from all over New Exodus marchers near New Brunswick, New Jersey.
the country. It was a vast, spectacular assortment of people, and the event itself was a success. But it did not have the feeling of a movement based on real power. The speakers were heavy on entertainment, light on political substance. Jesse Jackson and then Governor Celeste of Ohio offered some political support, but my clearest recollection of a speech is of actress Valerie Harper introducing every member of a contingent of television celebrities.

Despite the disorganization and disappointment, the Washington demonstration was an organizing success. It was sufficient to motivate members of Congress to move the National Affordable Housing Act (NAHA), the first legislation in years to substantially increase funding for low-income housing, out of committee, where it had been floundering for about two years. The act was passed in 1990, and its major component, the HOME program for low-income housing development, was funded for $1.5 billion nationally, beginning in 1992. Although NAHA is far from sufficient, there finally seems to be a move toward more federal involvement in low-income housing.

Backlash
The coalition of groups that constituted Housing Now! stayed connected after the 1989 rally and developed organizational structures, platforms, and various demonstrations and actions, including the march at Kennebunkport. It has been tough to stay focused. Mitch Snyder and CCNV cut back their support, and Snyder eventually took his own life in July 1990, leaving a vacuum in the articulation of homelessness as a national issue.

At the same time, I have been acutely aware of a shifting attitude toward the issue of homelessness as well as toward the people who are homeless. The public perception of homeless people is increasingly a vicious stereotype of lazy drug addicts on welfare who have only themselves to blame. In New York City there have been ordinances against panhandling, closing of parks frequented by homeless people, sweeps by the Transit Authority, and front-page news articles about homeless people getting over on the

system. As Jim Cain, associate director of the Ohio Coalition for the Homeless, says, "People who were at first sympathetic thought that homelessness could be fixed. Now that it's still with us, people are coping by blaming individuals, saying that it's not a housing crisis, it's not a lack of job training and opportunity. It's them."

Homeless people do not vote in large numbers or contribute to political campaigns. With moderate income people themselves on shakier financial ground, they are less likely to be giving what may seem to them to be handouts. "People will still say they support helping the homeless," says Pat Burton-Eadie, shelter director for the Partnership for the Homeless, a service and advocacy organization in New York City. "But if you want them to do something, even make a phone call to an elected official, forget about it." The Partnership still gets some volunteers and donations, but Burton-Eadie says that she sees "more antagonism than support."

Among activists themselves, the mood is low. Meetings to organize for Kennebunkport were usually composed of a handful of well-intentioned advocates. I gauge the effect of a housing demonstration as much by the leadership skills homeless people learn in working to organize it as by the assembly of numbers and the impact of the rally. Working with homeless leaders is always difficult because of their low self-esteem and tremendous survival needs—the same problems that compound their economic and political oppression. But there is a feeling across the board of treading water—that all of our hands are cuffed behind our backs as we flail our legs in the water.

The Next Step
The lull in activism and the backlash against homeless people appear to be the results of the immensity of homelessness, as well as the institutionalization of it as a social problem. As the problem of homelessness intensified into a crisis in the 1980s, advocates as well as government approached it as a temporary problem unto itself that could be fixed. A decade later, we're stuck. We know that the problem is more than one of not enough housing. The needs associated with homelessness are complex, related to education, health, addiction, and personal support and rooted in a system that has long been insufficient to meet them. But programs to address these issues remain grossly inadequate, while emergency programs established to provide food and temporary shelter are becoming institutionalized. Social services to deal with the fallout of this deep neglect are becoming economically and politically entrenched.

Activism around homelessness is becoming more locally focused in two ways. One is attention to public policy. With federal funds beginning to flow again to some degree, advocates and service providers are focused on lobbying for increased funds and making sure money comes into their local areas in the most effective ways possible.

The other focus is what could be called the core of homelessness: the despair that is the legacy of abuse, neglect, distrust, and lack of education and job skills. This profoundly compounds the dearth of housing units and creates a critical need for intensive work as well as compassion for people who are isolated, angry, and hurting. It also places demands on public officials to increase drug treatment programs, support education, and make jobs and training more available. It is cruel to tell people "pick yourself up" when support systems fall desperately short of the need. This is a tall order, but I find my own work increasingly focused on this core, and virtually every conversation I have these days with activists and service providers includes some reference to this.

For me, as an organizer and activist, this is a time of waiting—trying to listen to what homeless people need, reflecting on the successes and difficulties of past approaches, and focusing attention to where change is possible at this time.

The urgent truth of people's lives is up against an uncertain social and political climate. For me, it's that urgency that keeps this waiting period active. The options that homeless people and their advocates have to resist an unjust and complex situation may be limited, but the will to resist does not change so easily with the political winds.
Bush Declares Open Season on OSHA

by David Kotelchuck

In his January 28 State of the Union address, President George Bush fired a double-barrel shotgun blast against workers' health and safety protections:

I have asked major Cabinet departments and Federal agencies to institute a 90-day moratorium on any new Federal regulations which could hinder growth. In those 90 days, major departments and agencies will carry out a top-to-bottom review of all regulations, old and new, to stop the ones that will hurt growth and speed up the ones that will help growth.

The president calls this a policy to promote economic growth. But the only growth it will certainly promote is in injuries, disease, and death on the job. More workers will be hurt, more will get cancer, and more will die because of this policy.

Standards Delayed

Let's look first at the standards that the Occupational Safety and Health Administration (OSHA) is now working on. According to the "Semiannual Agenda of Regulations," which the U.S. Department of Labor issued on October 21, 1991, OSHA is currently working on no less than 44 new or revised federal health and safety standards. According to the president's speech, work on these regulations will be delayed for at least 90 days, since he has often stated (incorrectly) that workplace regulations hold back economic growth.

Here are just some of the 44 regulations that will be delayed:

- **Ergonomic safety and health standards.** Repetitive strain injuries are now the leading cause of workplace illnesses in the United States. They cause carpal tunnel syndrome and tenosynovitis among production-line workers in many manufacturing industries and among clerical workers using video display terminals. Stopped for 90 days.
- **Methylene chloride.** This solvent has been found to cause cancer in animals and is suspected to cause cancer in humans. It is used by workers in many degreasers, sprays, and other compounds. Standard delayed for 90 days.
- **Cadmium.** This metal and its compounds are highly toxic. Evidence has recently been found that it causes cancer in humans. Cadmium compounds are widely used in electroplating, welding rods, and silver solders and as coloring agents in many paints. Work on standard delayed for 90 days.
- **Lead in construction.** The current OSHA lead standard does not cover construction workers. OSHA was finally supposed to announce a special lead standard for construction workers in May 1992. Work on this new standard delayed for 90 days.
- **Indoor air quality in the workplace.** Indoor air contaminants cause eye, nose, and throat irritation, headaches and nausea, as well as illnesses such as Legionnaire's disease. It is the source of many workplace health complaints, and a standard is badly needed. Work delayed by 90 days.
- **Confined space entry.** This is a frequent cause of deaths on the job, yet no OSHA standard specifically deals with the hazards of entering dangerous confined spaces. OSHA was working on such a standard. Work halted for 90 days.
- **Scaffolds.** Stopped for 90 days.
- **Fall protection systems.** Stopped for 90 days.
- **Respiratory protection.** OSHA was updating its 20-year-old respiratory protection standards. Halted for 90 days.
- **Crane safety.** Halted for 90 days.

In a 90-day period, probably several American workers will die from entering dangerous confined spaces; others will die in crane and scaffolding accidents. Some will develop...
cancer from cadmium or methylene chloride, although they might not discover it for 20 more years. Hundreds will develop carpal tunnel syndrome, and their pain will linger for many weeks or months.

This is not an acceptable price to pay for the production of goods and the construction of buildings. In any case, it's not a price that George Bush and his friends will pay.

Revoking Regulations

So far, we’ve been talking about the first, most publicized Bush attack against workers’ health and safety. But there is another, even more dangerous threat against OSHA in the president’s speech: He is going to review all existing regulations and “stop the ones that will hurt growth.”

George Bush, like Ronald Reagan before him, never met an OSHA regulation that didn’t hurt growth. So what the president is really calling for is an open season on all existing OSHA regulations.

The president, through his Secretary of Labor Lynn Martin, has the power to revoke existing OSHA regulations, according to the provisions of the OSHA law. In fact, George Bush did just this in 1981 as vice-president, under authority from President Ronald Reagan. Just as the Reagan administration was taking power, Bush revoked the OSHA Right-to-Know Standard, the OSHA Hearing Conservation Standard, and the so-called Generic Cancer Standard, among others.

An opening salvo of the Bush administration’s attack on OSHA was recently fired by the Office of Management and Budget when it blocked a comprehensive revision of OSHA standards for air contaminants in agriculture, construction, and maritime work—among the most dangerous occupations in the country. OMB claimed that more workers would suffer adverse health effects from wage and job cuts that would result from the expense of implementing the new standards than the standards would protect.

Faced with ridicule from critics such as Edward Kennedy, who characterized OMB’s explanation as saying that “healthy working conditions are bad for workers’ health,” the agency quickly modified its action and allowed the regulations to be published while inviting public comment. Nevertheless, I believe President Bush is preparing once again to revoke important OSHA standards. We must be on guard to alert, educate, and mobilize workers, unions, and our communities against such actions.

Our country’s economic slide was not caused by protecting workers’ health and safety. And we will not let the economic slide be a smokescreen for attacking our health and safety, either.

Media Scan

Public Health, Private Blame


by Howard Berliner

It public health is so good, why do we have less of it? How can something so universally beloved get such bad treatment when it comes time to allocate the public budget? This slim volume makes one ask these questions, but it does not provide any answers to them. As a hortatory tract to raise consciousness about public health and primary care, this is an excellent book. It cannot be read without anger and dismay at the dissolution of the public health infrastructure in New York City. The weakness of Imminent Peril is the lack of any analysis of why public health is being defunded.

The essays were assembled at the request of the editor, the senior member of the New York City Board of Health, after the Department of Health was threatened with overwhelming (25 percent) cuts in its budget for fiscal year 1992. The papers lament and decry these cuts and wax eloquent about how harmful they will be, how cost-ineffective and unnecessary they are, and how things were better in the old days. Yet the very people who bear responsibility for cutting budgets for public health—representatives of the White House (Deborah Steelman), Congress (Charles Rangel), New York State Governor Cuomo, and New York City Mayor Dinkins—all have chapters in this book blaming someone else for the cuts. In the introductory chapter the editor presents the villain as the (unnamed) Woodrow Myers, Jr., the former Health Commissioner of New York City, who resigned before the cuts were announced. There is no attempt, editorial or otherwise, to get these authors to accept responsibility for their actions or even to explain them. Mayor Dinkins admits to “tremendous personal pain” at having to cut the budget, but he is “particularly proud of the restorations we have made to programs that affect the future of our city—our
children.” It should be noted that the restorations are not significant. Governor Cuomo apparently suffers no pain nor has any pride in his 15 percent cuts at the State Department of Health, because it is all the fault of Ronald Reagan and George Bush. And so it goes.

The book begins with chapter by Professor John Duffy, whose previous two-volume history of public health in New York City remains the germinal work in the field. Yet Duffy does not get beyond the 1940s. This leaves the reader with the sense that 1991 was the only year a public health budget has been cut. What about the massive cutbacks during the fiscal crisis of the 1970s? Were there similarities in the process or the outcome? Why is only Woody Myers blamed for not planning for the future but not Stephen Joseph, his predecessor at the department of health? These questions, and many others that naturally arise, remain unanswered.

**Government Investment in Health**

Since the mid-19th century, it has been clear that actions by the state have an impact on the health of the population. The level of government investment in health and welfare programs is inversely related to mortality and morbidity rates. When the government makes a substantial investment in the public health, mortality and morbidity rates go down; when that investment decreases, sickness rates and deaths rise. The level of investment, and hence the health of the population, depend on the amount of pressure that can be brought to bear on the government.

By this analysis, crude as it is, the decrease in public health spending on federal, state, and local levels indicates a clear attempt to reduce the size of the supported population. In this regard it is notable that the only level that has been cut is the federal. State and local health budget of the health department in New York City. In the fiscal crisis of the 1970s, there was a decrease in public health spending. The level of government intervention has reduced the effectiveness of the active health services, they will have to fight for them, because on its own government will not.

It is of interest that public health is portrayed as solely primary and preventive care services for the poor population of New York. Traditional public health functions (which affect the entire population) have been removed from the domain of the Department of Health. Thus, the assurance of water and air quality have been moved to the Department of Environmental Protection; food quality has been shifted to the Federal Department of Agriculture, the private sector supplies immunizations, health education, and preventive services for the entire population. Thus, poor residents of New York City are the direct and sole targets of the cuts in the Department of Health budget.

There are other questions that are not addressed in the volume, but should be. Is it possible to cut the budget of the health department without wreaking havoc on the population? Can the efficiency of the work force be improved or can programs be made better with fewer resources? Has public health (in its limited definition of primary and preventive care services for poor people) been effective in its mission—do health statistics show any improvement for this particular population group given the resources that have been invested? Is there a better way to provide these services than what is currently being done?

Cahill ends the volume with the instruction that the imminent peril that the city faced in the summer of 1991 must not be allowed to develop again. Unfortunately, we are still in imminent peril, and nothing in this volume will serve as an aid to getting us out. Its usefulness may be in getting people to think about public health and how to assure and maintain it.

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When a close friend tested positive for the human immunodeficiency virus (HIV), he called me for help. Because I have worked in AIDS for several years, I guess we both assumed that I'd be able to lend not only emotional support, but also some practical advice. After giving him the telephone number for Body Positive, I realized that there wasn't much more that I could offer to someone who was "just positive" and in fairly good health. A few days later we combed the AIDS sections of area bookstores and found quite a number of books about living with AIDS, but literally nothing about living with HIV, or being HIV-positive and asymptomatic.

This relatively new need speaks to the changing situation of those affected by HIV. With the approval of antiviral drugs and a greater number of treatments for opportunistic infections, more and more people are finding out their HIV status before they develop any symptoms. Because HIV infection rates are continuing to escalate alarmingly, more people than ever before are in need of information and assistance, and often concerns go beyond the medical. Indeed, knowledge of one's HIV status affects the life of the infected person emotionally, psychologically, interpersonally, sexually, financially, socially, and even culturally. With all these ramifications, it is easy to become overwhelmed.

A guidebook can be a great source of empowerment for people who suddenly find themselves affected by this unpredictable and potentially devastating virus. Through reading, affected individuals can gain knowledge, power, and strength—the tools with which to fight the virus and regain control of their lives. Such a book may help to reduce feelings of helplessness, powerlessness, and inadequacy for the HIV-infected as well as caregivers (and the categories are by no means mutually exclusive).

The Guide to Living with HIV Infection addresses the needs of people living with HIV in a clear and concise manner. The book's approach is carefully planned, and its articulate discourse provides reassurance. In a fundamental way, The Guide to Living with HIV Infection offers the reader a model for creating order from the chaos a diagnosis of HIV often creates. This book is not only helpful for the newly diagnosed, but it is sophisticated enough that the seasoned "professional" can learn something. Bartlett and Finkbeiner take the reader clearly and simply through "what to do when first diagnosed," for example, which had remained until recently a learn-as-you-go process. The authors continue along in their lucid, systematic method, covering a host of factors that affect HIV-infected people, ranging from the legal and financial to the emotional and interpersonal. The book falls short on a few points that seem to result from their scientific style, but despite these minor faults, it remains an excellent guide for anyone dealing with HIV.

User Friendliness

The book portrays itself as a "user-friendly" handbook or manual for "living with" the virus. While to a great extent it delivers, the language in this guide becomes somewhat "doctor-ish" in spots. Considering that the only prevention that we have is education, it becomes vital that anyone reading this regardless of educational level will be able to read, comprehend, and ultimately utilize the terms. Medical terms and procedures are often difficult for people new to HIV to understand. However, people move from novice to expert fairly quickly in HIV, whether due to the scarcity of information or the intensity of individual interest, but readers may find it easier to relate to discussions of cunnilingus and fellatio if the

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James Cassese is volunteer coordinator for a major AIDS service organization and maintains a private psychotherapy practice in New York City.

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by James Cassese
For those well-versed in HIV, it is to HIV, the book is simple and direct. It also appeals to readers with a wide range of experience. For people new to HIV, the book is simple and direct. For those well-versed in HIV, it is comprehensive and lucid. And for those learning about HIV, there is enough in this guide to maintain interest and keep informing the reader. This book can be read and put up on the shelf to be reread later without losing its currency.

Unfortunately, at times this guide becomes overly instructive and is plagued with imperatives. While other chapters are written for the HIV-positive person, The Guide to Living with HIV Infection meets this standard for a handbook; it has not yet outlived its usefulness. It also appeals to readers with a wide range of experience. For people new to HIV, the book is simple and direct. For those well-versed in HIV, it is

terms were replaced with “going down on” or “blow job.” Although the authors carefully suggest practical ways for the average person to address a potential partner regarding safer sex, their use of such clinical language does not offer much help to the reader attempting to apply the information to negotiate safer sex. How does “fellatio” fit into an attempt at a natural-sounding sex conversation? Better to be direct and safe than clinical and unprofitable.

The bigger problem with any kind of HIV guide or handbook has been that it can become outgrown, outmoded, or outdated rather quickly for people living with HIV. The Guide to Living With HIV Infection meets this standard for a handbook; it has not yet outlived its usefulness. It also appeals to readers with a wide range of experience. For people new to HIV, the book is simple and direct. For those well-versed in HIV, it is


Everyone needs to know about AIDS, but people need different information and need to hear it in different ways. Faced with the urgency of educating the public about the AIDS epidemic, Media Network has produced Seeing Through AIDS, an alphabetical listing with reviews of over 70 “alternative” films and videotapes that has something for audiences of every age, ethnic group, and level of information about the epidemic. (The 1989 guide is updated in a pull-out supplement to the Winter 1992 issue of Immediate Impact, Media Network’s quarterly newsletter.)

Media Network, an organization of producers and users of film and video dedicated to social change, has selected films that aim to counter the “homophobic, racist, sex-phobic, moralizing and stereotyping depictions” of the mainstream media, as well as to “enrage and challenge audiences.” The productions range from three-minute shorts to full-length films and from the instructional to the provocative. They cover such topics as health education, safe sex, AIDS activism, and representations of people with AIDS. The guide’s helpful features include indexes to subject matter and suggested audiences, lists of media distributors and other resources on AIDS, and eminently practical guides for running film screenings (for example, how to lead a discussion and how to use the equipment) and for getting access to local television.

Among its other media guides, Media Network also publishes Choices: Women’s Reproductive Freedom and Health, and a guide to films on health care policy is in the works. In addition to its publications, the organization maintains extensive listings of films and videos on various social issues, sponsors independent film producers, and hosts conferences and workshops on using media for social change. Media Network may be reached at 39 West 14th Street, Suite 403, New York, NY 10011, (212) 929-2663.

—Ellen Bilofsky

Clarity and Reassurance

One helpful aspect of this guide is that the chapters do not need to be read in order. A caretaker can pick it up at Chapter 7, “AIDS Dementia Complex: HIV and the Central Nervous System,” or read about “Medical Treatments” in Chapter 9. A newly diagnosed person may begin with Chapter 1, “When First Diagnosed: Understanding and Communicating about HIV.” Or even better, everyone can read Chapter 2, “Preventing Transmission of HIV Infection: Understanding How HIV is Spread,” which is quite good. This chapter is not only easy to read, but actually accomplishes the herculean task of addressing preventive measures without inciting fear and panic. Indeed, this chapter is actually reassuring, if that’s possible. HIV affects interpersonal relations and communication at many levels. More than whom to tell or when to tell, there is the consideration of how to protect oneself as well as one’s partner. This is clearly and system-
At the University of California at Santa Barbara, researchers have designed a website that provides a continuous summary of the current status of HIV and AIDS research. The website, available at http://www.hivnet.ucsb.edu, is updated daily and includes news, research articles, and resources for researchers and the public.

The website is part of the University of California at Santa Barbara's Center for AIDS Research and Education (CARE). It is one of the first websites to provide a comprehensive overview of HIV/AIDS research, including updates on new therapies, the latest research findings, and information on the social and economic impact of the disease.

The website is designed to be user-friendly and accessible to a wide audience, including researchers, healthcare providers, educators, and the general public. It includes a search function, a glossary of terms, and links to other relevant websites.

The website's creators hope that it will help to increase awareness of the latest advances in HIV/AIDS research and provide a valuable resource for those working in the field.
neurosyphilis, to which men and drug users are also prone, are not included in the standards.

The biggest change, however, is the addition of a stringent four-part functional test that is applied to claimants who have certain medical conditions that are not included in the current CDC definition of AIDS, such as persistent bacterial pneumonia and persistent pulmonary tuberculosis or sepsis. According to the new SSA standards, certain medical conditions that are not considered AIDS-defining by the CDC may now be considered factors contributing to disability. So SSA may now judge a claimant with meningitis, for example, disabled, but only if he or she can also prove having at least two of four functional impairments. Certain medical conditions, such as mucosal (including vaginal) candidiasis require proof of one of a list of infections in addition to the functional impairments.

One functional criterion is repeated episodes of decompensation lasting more than two weeks and occurring every four months. According to Webster’s dictionary, decompensation refers to the inability of the heart to maintain adequate circulation. Of the roughly 15 Social Security representatives I asked about it, only two had heard of it. One defined it as a marked worsening of a medical condition and another thought it was a legal term. Another functional test requires the claimant to prove marked difficulty in maintaining social functioning—a criterion that is not only hard to measure, but is also a better indicator of one’s psychological condition than one’s ability to work. Many people with HIV maintain a high level of social functioning while gravely ill.

The functional tests are an unnecessarily harsh barrier to obtaining benefits and add a layer of bureaucratic obstacles to the process. Three of the four tests require the claimant to demonstrate a “marked” difficulty in functioning, although “marked” is left poorly defined and therefore difficult to prove. And all of the tests require evaluation and documentation by a physician, making it more difficult for people without their own primary care physicians to qualify.

SSA’s use of functional tests to evaluate physical impairment as part of their regulatory listings of impairments that expeditiously qualifies a person for disability benefits is unprecedented. No other adult disability, with the exception of those caused by mental health conditions, requires functional assessment. Requiring functional tests in the regulatory listings for certain medical conditions—typically those experienced by women, drug users, and poor people—discriminates by holding those who do not have certain approved conditions to a more stringent standard, and keeping much-needed benefits from them. Disability and AIDS advocates alike recognize that this departure sets a dangerous precedent for people seeking benefits for any type of disability.

The Suit

Somatic hope for creating fairer standards lies in the class action suit S. P. v. Sullivan, filed by MFY legal services and four other legal services offices, brought against SSA on behalf of 11 HIV-infected individuals and all others who were denied Social Security benefits although they have severe HIV-related impairments. The plaintiffs have experienced a wide range of conditions, including pneumonia, chronic fatigue, vomiting, weight loss, lung abscesses, cervical carcinoma, and recurrent candidiasis. Some applied for benefits as far back as 1985, and some have died waiting.

SSA moved unsuccessfully to have the case dismissed and may make another such motion based on the fact that the suit was filed before their latest standards were proposed. Yet, the problem remains: only those with certain HIV-related impairments are entitled to a quick determination of disability and are considered disabled. Others who experience HIV disease differently—women, drug users and the poor—are not, unless they can adequately document that they meet SSA’s four-part functional test.

The formal listings were proposed in December, when the period for public comment also began. At that time, SSA also adopted the proposed listings in an internal administrative ruling. While the period for commenting on their proposal ended in February, the agency is not likely to respond quickly to the 3,500 comments they received (in the past they have taken three years to respond to comments on comparable regulations). As one representative candidly told me, he could not discuss the regulations until they are finalized and, yes, that might take as long as three years.

Although the regulations may be finalized before the end of this year, letters demanding the unqualified inclusion of the full range of medical conditions in SSA’s HIV-related disability listings may still be helpful, especially from health professionals. Letters may be addressed to Louis Sullivan, United States Secretary of Health and Human Services, or Gwendolyn King, Commissioner of Social Security, at the Department of Health and Human Services, PO Box 1585, Baltimore, MD 21203.
Primary Care in Australia

It's with great pleasure that I read the Health/PAC Bulletin when it arrives each quarter. The Australian health care system seems benign in comparison to the USA, which is a good perspective to have when we may have had (and lost) some major battles to reorient the health system. I'm particularly appreciative of the analysis of health care in relation to poverty, race, and sex issues that emerges each issue.

I have enclosed a copy of the Manual of Standards for Community Health or CHASP [Community Health Accreditation and Standards Program], a project of the Australian Community Health Association. CHASP is based on 5 core principles for community/primary health care:

- Responsibility for the main health needs of a defined community.
- Equity and accessibility.
- Comprehensive program content (health promotion, primary health care).
- The participation of people in debate and decision making about health issues.
- Multidisciplinary approach.

CHASP was developed in the early 1980s, and now operates in most Australian states. It has a unique review process based on action research methods, for health workers to reorient and improve their services. CHASP has been shown to be very flexible for all types of services and all sizes. We are involved in adapting the standards for use by aboriginal health services in remote settings as well as for small rural hospitals attempting to broaden their role.

We are keen to let people outside Australia know about CHASP in case it would be useful for their practice of primary health care. We will be establishing a program in New Zealand next year—our first step outside Australia.

PENNY RYAN
National Coordinator, CHASP, 27-33 Spring Street, P.O. Box 657, Bondi Junction, 2022, Australia

Urgent Medical Need in Peru

By way of this letter, we introduce ourselves as a group of missionaries who went to Peru last summer to teach the Bible. While there, a group of Peruvian doctors petitioned us to help them administer aid to the poor people in their country, especially the children. They asked us to bring back certain medicines and medical supplies when we return in June of 1992.

We were not, and are not, making plans to become a medical mission. While in Peru, however, medical needs were made known to us. Through supplies we had brought to care for ourselves, or minimal extra funds we had available, we tried meeting these people's needs.

For example, a Peruvian grandmother heard there were Americans in town and brought her 3-month-old granddaughter to us for help. The doctors said that the purplish growth on the child's neck was a tumor. It reached from the nape of her neck to her chin and was swollen into three folds. The family was told that perhaps the doctors in Lima could help by performing surgery, but probably a child of this age with a tumor that size would not survive. The newspaper the next day ran an article about some American doctors in a town 50 miles away, so we took the baby there to see if we could get help. The problem was found not to be a tumor, but in fact a severe infection. This was treated with an iodine wash and antibiotics, and when we left Peru over a month later, it was greatly improved.

Many times the people would petition us for finances to buy medicines. The families managed to get to a doctor, but could not afford to fill the prescriptions. We were very surprised at the cost of these medicines—between $40 and $80—and we often had to go to two or more pharmacies just to find the correct medicine. Because of our personal experiences, we know that there truly is a shortage of medicines and equipment.

These doctors work solely with the poor, and principally with children, usually without payment of any kind. They report that daily they watch their patients die because they have neither the instruments nor the medicines necessary to save them.

Peru is in a state of serious economic depression. The inflation rate last year was 360 percent, and 75 percent of Peruvians live below the U.S. poverty level. For this reason, their government can offer them no help. The doctors have independently formed an association to regulate these medicines and to insure they are not sold on the black market.

Our hope is that your readers may be moved to assist us in this campaign of mercy. Because we are a group of missionaries, any donations made would be tax deductible.

MARJORIE LINDHOLM

For more information, to request a list of medicines and equipment needed, or to make donations, contact Ms. Lindholm at 1213 North Cleveland, Kennewick, WA 99336, (509) 783-5762.
The Disability Rag is our Village Voice, Rolling Stone and Mother Jones all rolled into one small but powerfully written tabloid.

- Edward Hudak, Detroit Free Press

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HEALTH/PAC BULLETIN
Covering the Crisis in Health Care...and Beyond

The Health/PAC Bulletin, the nation’s longest-publishing progressive health policy journal, has been in the forefront of health rights advocacy for nearly 25 years. Our demand is simple—decent, accessible health care for all—but our analysis of the health care crisis is thorough and in depth.

Published by the Health Policy Advisory Center, a non-profit, public-interest membership organization, the Bulletin looks beyond stop-gap measures to the heart of the health care crisis. Recent issues, for example, have examined the gaping holes in the health care safety net that threaten the very survival of large and growing segments of the population, especially the poor and people of color.

But, the Health/PAC Bulletin also goes beyond this analysis to explore progressive solutions to the health care crisis that could make “health care for all” more than just a slogan and highlight the work of today’s activists, fighting against homelessness, HIV, and violence. If you believe health care is everyone’s right...

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