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Robert A. Padgug

Gerald M. Oppenheimer

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AIDS, HEALTH INSURANCE, AND THE CRISIS OF COMMUNITY†

ROBERT A. PADGUG*
GERALD M. OPPENHEIMER**

Almost alone among modern industrialized nations, the United States has chosen to finance the provision of health care to its citizens through a patchwork system centered around employer-sponsored private health insurance. Employer-sponsored insurance is, at least in part, supplemented by government entitlement programs, most notably Medicare and Medicaid, for those excluded from private insurance either because, like the elderly and the disabled, they utilize too many services, or, like the poor, they cannot afford to purchase it. Private health insurance therefore represents, in our system, access to health care itself for the largest portion of the population.

During the early years of the epidemic, AIDS was seen as a major challenge to this unique American health care financing system. It was commonly asserted that AIDS would inevitably undermine the financial stability of the private health insurance industry and, ultimately, its ability to provide health insurance to the American people. This assertion was, to some degree, based on early cost estimates which suggested that the lifetime hospital cost per individual with AIDS was as high as \$147,000.¹ One officer of one insurance carrier saw AIDS metaphorically as a natural catastrophe, akin to floods, which only the federal government, with all its resources, could cover.²

As the epidemic has unfolded it is increasingly clear that such assertions were highly alarmist and, indeed, self-serving on the part of some in the health insurance industry.³ AIDS

† The opinions expressed in this article are those of the authors and do not necessarily represent the views of the institutions at which they work.

* Ph. D. , Empire Blue Cross and Blue Shield, New York City.

** Ph. D. , Brooklyn College of the City University of New York.

1. Hardy et al, *The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States*, 225 J. A.M.A. 209-11 (1986).

2. Steve Rish, Vice-President of Nationwide Insurance Company, *quoted in Gay Community News* (Boston), Sept. 21, 1986, at 11.

3. See Jesse Green, Gerald M. Oppenheimer and Madeline Leigh, "The \$147,000 Misunderstanding: Overstating the Cost of AIDS," paper presented at the Fifth International Conference on AIDS, Montreal, June

has, to be sure, proved to be an expensive ailment, but its life-time costs, most commonly estimated in the \$50-80,000 range (in current dollars), are no higher, and often lower, than those for comparable catastrophic illnesses. More significantly, the aggregate costs of AIDS to date and for the foreseeable future represent no more than a small proportion—1 to 2% at most—of total U.S. health care expenditures.⁴ Certainly, no health insurer is in danger of bankruptcy due to the costs of AIDS. This applies even to those insurers, such as Empire Blue Cross and Blue Shield in New York City, which have borne the brunt of those costs due to their large market shares and relatively generous underwriting policies.⁵

Ironically, although AIDS has posed a minor threat to health insurance, health insurance has dramatically, and negatively, affected persons with AIDS and those perceived to be most at risk for it. It is now apparent that the manner in which American health insurance is organized and the serious crises that have marked its recent history have posed a substantial threat to our ability to handle the AIDS epidemic itself in an efficient, compassionate, and equitable manner. The threat derives less from discriminatory or illegal activities on the part of the insurance industry, although these certainly have been present, than from the ordinary manner in which that industry operates.

In essence, the competitive demands of the insurance industry have, over the years, forced it continually to narrow the pools within which the costs of health care are spread. The remaining private insurance pools now cover a declining proportion of persons in the community and, most significantly, exclude those with the greatest need to be covered.⁶ In effect, the industry's need for profitability and financial efficiency have made it difficult, if not impossible, to offer insurance, and thus an appropriate level of health care, on an equitable basis to all who need it in the community.

1989, and Fox & Thomas, *The Cost of AIDS: Exaggeration, Entitlement and Economics*, in *AIDS AND THE HEALTH CARE SYSTEM 197-210* (L. Gostin ed. 1990).

4. See the works cited in the preceding note and Scitovsky, *Studying the Cost of HIV-related Illnesses: Reflections on the Moving Target*, 67 *THE MILBANK Q.* 318-44 (1989); Hellinger, *Updated Forecasts of the Costs of Medical Care for Persons with AIDS, 1989-1993*, *PUB. HEALTH REPORTS*, Jan./Feb. 1990.

5. See Jon Eisenhandler & Robert Padgug, "Empire Blue Cross and Blue Shield: the First 7,500 Cases," paper presented at the Fifth International Conference on AIDS, Montreal, June 1989.

6. Cf. Oppenheimer & Padgug, *AIDS: The Risks to Insurers, the Threat to Equity*, 16 *HASTINGS CENTER REP.* 18-22 (1986).

The situation is substantially complicated by the fact that this crisis of "community"—the dilemma of inclusion and exclusion—within the insurance world has intersected with and been compounded by an equally serious challenge created by the AIDS epidemic itself. AIDS challenges our sense of what constitutes the legitimate boundaries of the larger American community. This second crisis stems from what is perhaps the single most notable aspect of AIDS, its demography: it has, to date, mainly struck members of very specific groups, in particular gay men and IV drug users, who were, even before the emergence of AIDS, often disliked and considered outside the boundaries of American society.

Both gay men and IV drug users are perceived by many to be the "carriers" of a deadly and terrifying virus and the victims of a disease they in some sense brought on themselves. As such, they are considered by some to be undeserving of sympathy for, and assistance in bearing the burdens of, those serious or catastrophic problems that periodically occur in most of our lives. With respect to insurance in particular, this status as outsiders leaves both groups even more vulnerable than others to all of the problems created by narrowing risk pools and other insurance crises.

These intertwined problems of exclusion and the breakdown of community have created a serious threat to the access of gay men, IV drug users, and, in particular, persons with AIDS, to insurance and, thus, to necessary health care. This threat and its causes raise significant policy questions that are relevant not only to the AIDS issue but to all of American society: Is there an unresolvable contradiction between society's need to establish equity in the provision of health care and the insurance industry's needs to safeguard its economic profitability and efficiency? Can the United States meet the challenge of equity for AIDS patients within the parameters of the current system of health care financing? Specifically, can the current system develop a mechanism for including the whole community of individuals within its domain?

In order to comprehend the threat to health care access and the policy issues it raises more closely, we will, in the remainder of this essay, mainly focus on the private health insurance system and the particular situation of gay men, and to a lesser degree IV drug users, within it. Gay men are central both because they are more likely to be covered by private insurance than are other groups affected by AIDS and because the effects of private insurance on them and their reaction to it are relatively well known.

II.

In the 1930s, when the Blue Cross and Blue Shield plans created the policies which served as the prototypes for our current health insurance system, insurance premiums were based on what is known as community rating. That is, the costs of health care were spread among the entire population, or community, that was covered by a particular type of policy, and premiums were set at the same level for everyone.⁷ This system represented a broad spreading of the risks, and thus the costs, of health care utilization over a relatively large population.

The original principle of community rating was substantially replaced over the next few decades by what came to be known as experience rating. The main cause was the shift to an employment-centered health insurance system. As employers began to provide their employees with health insurance during the 1940s and 1950s they insisted, in the interest of keeping costs as low as possible, that their premiums be based only on the actual health care utilization of their individual employee groups, normally made up of younger and healthier persons than the population in general.⁸ Commercial insurers, seeking a market for themselves, were only too happy to comply, and eventually most Blue Cross and Blue Shield plans were forced to follow suit in order to survive. Insurance risks were thus spread among a relatively small base, with some, such as the elderly, the unemployed, the chronically ill, and the poor, in large measure left out of the system. Even small groups and individual purchasers of insurance, who continued to be lumped together in larger pools, felt the effects of this development, as adjustments were made to their premiums for age, sex, industry, and geographical location, factors considered to be closely correlated with health care utilization.

By the 1970s, this trend proceeded to the next logical step: in order to reduce costs further, and to escape from state legislation and regulation, large employers instituted what is called self-funding or self-insurance, paying the health care costs of their employees directly from their own funds and eliminating the insurance company entirely, except for certain administrative functions.⁹ The effect of this trend, which has by now been extended to perhaps 60-70% of large employer groups, is that

7. R.D. EILERS, REGULATION OF BLUE CROSS AND BLUE SHIELD PLANS 88-91 (1963).

8. Cf. R. STEVENS, IN SICKNESS AND IN WEALTH 260-62 (1989).

9. Rublee, *Self-Funded Health Benefit Plans. Trends, Legal Environment, and Policy Issues*, 255 J. A.M.A. 787-89 (1986).

the risks of health care, which even in the days of experience rating were at least shared between employer and insurer, are now spread even more narrowly. An employer without "stop-loss" insurance—itself relatively expensive, with premiums based on health care utilization within the employer group—and with any significant number of sick persons will be in danger of unacceptable cost increases at best and fiscal insolvency at worst.

Already in the early 1960s, it was clear that the system was in crisis, since, although employer-sponsored coverage had grown immensely, a large portion of the population was excluded from it. The response to this initial crisis was to create Medicare and Medicaid, programs aimed specifically at those who were left out of the private insurance system. With these programs in place, it was believed that ultimately the entire population would be covered by some form of health insurance.

The health care financing system, now an amalgam of private and public insurance programs, did continue to grow for some years, but entered a renewed period of serious crisis when, beginning in the late 1970s and accelerating during the 1980s, both insurers and self-insured employers were confronted with substantial and continuing increases in the costs of health care. These cost increases have threatened the stability of the entire system, built as it is on the narrowest of risk-sharing bases. In the face of massive cost increases, insurer and employer interest in "cost containment" has, in part, shifted from pooling and insurance arrangements (insurance price constraints) to patient and provider behavior (health care demand/supply constraint) and, above all, to "cost-shifting" to those who use health care services.

For insurers, the crisis of costs has led to considerable tightening of underwriting rules in a further effort to exclude those at higher risk of using their health insurance. One major result has been that possibly a majority of small groups and individuals have now been excluded from most health insurance, adding annually to the pool of the uninsured, while even some larger groups are finding it difficult to procure insurance at affordable prices.¹⁰

For employers, the crisis has led to the desire or need either to drop health coverage entirely, in the case of many

10. Cf. Freudenheim, *Health Insurers to Reduce Losses, Blacklist Dozens of Occupations*, N.Y. Times, Feb. 5, 1990, at A1; Health Care Costs Disable Small Employers, J. Com., Feb. 9, 1990, at 1.

smaller employers, or, more commonly among larger employers, to shift a growing portion of their costs to the members of the group. Fewer plans, for example, now pay the entire premium for individual or family coverage, and the majority of employer plans have ceased to reimburse the full costs of even inpatient and surgical care, as they did earlier.¹¹ In addition, employers who are self-funded, and therefore no longer under the jurisdiction of state insurance laws, can trim their insurance packages to suit their needs, increasing employees' deductibles and co-insurance and decreasing the benefits offered. This trend, in which the cost of illness is increasingly shifted to the individual or family, is in many ways merely the logical conclusion of the movement from community rating to ever-narrowing insurance pools.

Thus the private insurance system had, by the 1980s, reached a serious impasse, which left a significant proportion of the population uninsured or underinsured. Unfortunately, this occurred at a time when government, both at the state and federal levels, was itself retrenching, trying to cut costs associated with medical and disability reimbursement and characterizing health care more as a commodity than a social need or entitlement.¹² Government entitlement programs were thus ill-prepared to extend their protection to those who were falling out of the private insurance system. The crisis of health care financing had adversely affected both the private and the public foundations of the system.

III.

The AIDS epidemic could not have emerged at a worse moment, coming to public notice precisely as the crisis of health insurance intensified. Ominously, the disease was perceived as extremely expensive, and its trajectory was uncertain. Inaccurate early cost estimates, as we have already noted, played an incalculable role in firmly establishing AIDS as a disease with unacceptably high costs in the public and professional minds. Both insurers and employers believed they had good reason, indeed necessity, to rid their rolls of persons with AIDS and those believed most likely to contract it.

11. See DEPARTMENT OF LABOR, BUREAU OF LABOR STATISTICS, *EMPLOYEE BENEFITS IN MEDIUM AND LARGE FIRMS, 1988* (1990), and EMPLOYEE BENEFIT RESEARCH INSTITUTE, *WHERE COVERAGE ENDS: CATASTROPHIC ILLNESS AND LONG-TERM HEALTH CARE COSTS* (1988).

12. See Fox, *AIDS and the American Health Polity: The History and Prospects of a Crisis of Authority*, 64 *MILBANK Q.* (Supplement 1) 7-33 (1986); cf. Fox & Thomas, *supra* note 3, at 199.

Insurers refused to cover groups containing persons with AIDS or to cover them as individuals. Many self-insured employers feared the financial consequences of having such persons among their employees. In both cases, the established risk pools were too narrow and too fragile to spread the costs of AIDS widely and therefore "dilute" them.

Just as significant, the insurance industry, following most clinical, epidemiological, and popular attitudes, from an early stage in the epidemic unfortunately identified all gay men as a risk group, indeed *the* risk group, for AIDS and, therefore, for incurring far higher than normal costs of health care. As a risk group in both the epidemiological and underwriting sense, gay men became a group of potential and in many cases actual uninsurables, a development assisted by significant prejudices against gay persons that have long existed within American society and that were reinforced by the AIDS epidemic.

Most insurers and some employers have not only attempted to remove gay men directly from their rolls, in spite of efforts by the National Association of Insurance Commissioners and others to ban the use of sexual orientation in underwriting, but have also used a variety of methods, the most notable of which has been HIV antibody testing for insurance applicants or new hirees, to accomplish the same thing indirectly.¹³ More rarely, but equally damaging, insurers or self-insured groups have attempted to impose unrealistically low caps on payments for AIDS or for AIDS-related drug therapies, caps that have not been used for any other major disease.¹⁴

The result has been that many gay men find themselves facing a tragic paradox with respect to insurance. Employment has traditionally provided health insurance, but the use of health insurance for AIDS or related conditions caused by HIV infection in many cases threatens to lead to loss of employment and uninsurability. Use of health insurance for AIDS or related conditions not only identifies one as a high user of health care and therefore a threat to the employer group, but also as a member of a group that some employers, at least, wish to exclude from coverage on both moral and fiscal grounds. In such circumstances, it is not surprising that as many as one-quarter of all persons with AIDS in the United States have no

13. See CONGRESS OF THE UNITED STATES, OFFICE OF TECHNOLOGY ASSESSMENT, *AIDS AND HEALTH INSURANCE* (1988).

14. Taravella, *Self-Insured Employers Limit AIDS Benefits*, MODERN HEALTHCARE, Feb. 19, 1990, at 52.

insurance at all, while an unusually large number are forced to rely upon Medicaid.¹⁵

Insurers, of course, claim that sound underwriting policy requires them to identify and eliminate from coverage risk groups with unacceptably high patterns of utilization. Otherwise, they argue, insurance would become financially unsound, and people with average patterns of utilization would be unfairly subsidizing those with higher ones. Their argument has a certain amount of truth to it. But what the insurers have never admitted is that the financial instability of their groups is largely a problem of their own making due to the narrow manner in which they have construed their risk pools. Further, their rejection of "cross-subsidies" among pools is neither an actuarial nor a natural law, but a policy choice to be debated. Finally, they have failed to see that dividing the community into narrow pools of supposedly homogeneous risk reinforces the tendency among some parts of the population to see those with a greater possibility of illness, in particular HIV-related illness, as a separate group—an unworthy "other"—that must be abandoned to its own devices. When those at risk are persons who were previously considered beyond the normal boundaries of the community—in this instance, gay men and IVDPUs—such a separation is rendered even easier.

The direct exclusion from health coverage of persons with AIDS and persons seen as likely to contract it is further reinforced and deepened by the interaction between the nature and demography of the AIDS syndrome itself and the employer-centered nature of insurance. Many persons with AIDS, for example, and a large number of gay men in general, have traditionally worked for small groups or have been self-employed, precisely the portions of the working population most likely to have low rates of insurance coverage to begin with. In addition, a large proportion of persons with AIDS belong to age groups (18-35) in which rates of insurance coverage are ordinarily lower than at older or younger ages.

AIDS has also indirectly reinforced employer and insurer actions by making it difficult for many persons with AIDS to continue to work and therefore eliminating their insurance cov-

15. NATIONAL COMMISSION ON AIDS, FIRST REPORT, reprinted in *AIDS Patient Care*, Apr. 1990, at 2-4; Roper & Winkenwerder, *Making Fair Decisions about Financing Care for Persons with AIDS*, 103 PUB. HEALTH REPORTS 305-08 (1988); Makadon, Seage, Thorpe, & Fineberg, *Paying the Medical Cost of the HIV Epidemic: A Review of Policy Options*, 3 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 123-33 (1990).

erage.¹⁶ The vast majority of those who find themselves in this position do not have continued access to coverage through the family policies of their spouses, since gay relationships are almost nowhere recognized as falling within the category of the family.

Legislative and regulatory initiatives that extend insurance coverage through mandated conversion to individual coverage or time-limited extensions of employer coverage at individual expense (COBRA) have mitigated this problem somewhat. These initiatives are, however, significantly vitiated by problems of inadequate coverage, in the case of individual policies, and greater expense than most individuals can afford, in the case of the continuation of membership in employee groups. In addition, and perhaps most important, the COBRA mandates are inapplicable to employer groups with fewer than 20 members, a type of employer group especially common in New York City, San Francisco, and some other urban areas most affected by the epidemic.

Thus both persons with AIDS and gay men in general have seen their access to health insurance seriously threatened during the AIDS epidemic. The threat has been reduced for many persons with AIDS by the availability of Medicaid and other government programs, at least in some of the states most affected by AIDS, but Medicaid has substantial disadvantages. These include the necessity to "spend down," that is divest oneself of one's assets; the lack of uniformity in its coverage—not all states, for example, cover the purchase of AZT and other pharmaceuticals for the treatment of HIV infection; and the unfortunate refusal of large numbers of health care providers to accept Medicaid due to its generally low level of reimbursement.¹⁷ Some states, including New York, where the idea was pioneered, use Medicaid funds to pay the premiums of those eligible clients with catastrophically expensive diseases who retain eligibility for private health insurance, but only a

16. Cf. Greenblatt, Yellin, Hollander, McMaster, Kidd & Filson, *Work Disability among AIDS Clinic Patients*, in ABSTRACTS FROM THE VTH INTERNATIONAL CONFERENCE ON AIDS, JUNE 4-9, 1989, Montreal, Canada (Ottawa: International Development Research Center, 1989), at 1032, Abstract T. H. O. 1.

17. Holman, *Paying for Physician Services in State Medicaid Programs*, 5 HEALTH CARE FINANCING REV. 99-110 (1984); Perloff, Kletke & Neckerman, *Physicians' Decisions to Limit Medicaid Participation*, 12 J. HEALTH POL., POL'Y & L. 221-35 (1987).

relatively small number of persons are covered under such programs.¹⁸

Even for those persons—probably a majority of gay men, if not of IV drug users—fortunate enough to retain their insurance, numerous problems combine to render that coverage considerably less than ideal. For those who must pay their own premiums, in part or in full, the cost can be devastating. And almost all existing policies contain provisions for co-pays and deductibles, which, even in the presence of so-called stop-loss provisions that limit the applicability of these features, can be significant, especially to lower-income persons. The necessity, in many instances, to pay for expensive services at the time they are rendered and wait for often considerable periods of time for reimbursement from the insurer or employer, adds substantially to the burden of cost as well.

In addition, many policies, even those provided by large employers, contain pre-existing condition clauses, which limit payment for illnesses considered to have begun before the effective date of the insurance contract. Such clauses limit the effective coverage of persons with AIDS unfortunate enough to have them invoked.

Finally, and in some ways most significantly, few policies cover all the care a person with AIDS or related illness is likely to require. Not all insurance, for example, covers pharmaceuticals well.¹⁹ Exclusions for so-called experimental drug therapies, in particular, are almost universal; but it is precisely such therapies that are, of course, particularly common in AIDS treatment due to the relative novelty of the syndrome.

Perhaps of even greater importance are those exclusions that affect non-acute care. Because most health insurance has been based on employment, it has tended to focus on acute care—that is, mainly inpatient hospital and physician care—and omit coverage for long-term care needs, such as nursing home and subacute home health care. Since AIDS is, in many ways, a long-term condition, parallel to the chronic illnesses traditionally associated with the non-working elderly, the tendency to

18. Taravella, *Programs Help Low-Income AIDS Patients Pay for Insurance*, 19 MODERN HEALTHCARE 9 (1989); Taravella, *Two Groups Join List of Organizations helping AIDS Patients Pay Medical Bills*, 19 MODERN HEALTHCARE 37 (1989).

19. See Letsch, Levit, & Waldo, *National Health Expenditures, 1987*, 10 HEALTH CARE FINANCING REV. 109-22. On the general problem of exclusion of needed services, cf., Rowe & Ryan, *AIDS: A PUBLIC HEALTH CHALLENGE: STATE ISSUES, POLICIES AND PROGRAMS. INTERGOVERNMENTAL HEALTH POLICY PROJECT. VOL. 2. MANAGING AND FINANCING THE PROBLEM* 6-14 (1987).

exclude coverage for long-term care is particularly serious and costly to persons with AIDS.

IV.

These inadequacies of the American health care financing and insurance system not only pose a danger to the health and well-being of individuals, but have placed immense burdens on the communities that are most affected by AIDS, in particular the gay community and, increasingly, the poor and minority communities. In the first and most obvious instance, those burdens are financial: as members of communities disproportionately affected by an expensive and deadly epidemic, gay people and others have had to bear the substantial costs of AIDS not met by the insurance system or by those government programs intended to supplement it. Because of this, there has been a sizeable, albeit impossible to measure, transfer of wealth, especially from the gay community, to other Americans, most notably providers of health care.

The gay community, in particular, has had to make up for the lack of insurance on the part of many of its members, as well as for the lack of adequate coverage of many services by existing insurance policies, through an outpouring of voluntary labor and the establishment of elaborate care-giving institutions of its own, such as the Gay Men's Health Crisis in New York or the Shanti Project in San Francisco and many hundreds of similar organizations throughout the United States. These community-based services utilize large amounts of volunteer labor, mainly from within the community itself; such services remain almost entirely uncovered by insurance or other reimbursement. And finally, but not least significantly, all communities affected by these problems have had to pay for the lack of adequate health care financing through the unnecessary suffering and death of at least some of their members.

These burdens of the epidemic on the gay and other communities are due not only to the disproportionate numbers of their members who have contracted HIV infection, but to a very real breakdown of the communal principle that such burdens should be shared by the entirety of American society. And this breakdown has had a "ripple" effect upon the states and localities in which gay people and IV drug users form substantial minorities of the population. The lack of a true communal approach to AIDS has meant that the State and City of New York, for example, have had to spend immense sums directly for the provision of health care or indirectly in the form

of Medicaid, leaving them ill-equipped to handle by themselves all of the problems associated with the epidemic or, indeed, the large number of other health care problems facing their very varied populations. Nor have the health care systems of these localities fared any better: the absence of health insurance for an unusually large number of persons with one particular disease has added to the financial and other problems of already over-burdened hospitals and other health care institutions.²⁰

Finally, the groups most affected by AIDS have been forced to struggle long and hard to be included in insurance coverage and the wider American community. Gays have been most organized and successful in this respect. Through their numerous legal aid groups (among them, Lambda Legal Defense in New York and National Gay Rights Advocates in California), PWA coalitions, AIDS caregiving groups (such as Gay Men's Health Crisis in New York), lobbying groups (such as the Washington, DC, based National Lesbian and Gay Task Force) and, most recently, direct political action groups (most notably New York's ACT-UP, the AIDS Coalition to Unleash Power), they have struggled in many spheres and in many ways. Among these struggles have been those against insurance company practices—"redlining" of industries or geographic regions, use of HIV antibody testing to eliminate HIV positive persons from coverage—which limit the availability of coverage to gay people and people with AIDS and which limit the usefulness of existing health insurance. Other struggles have been against discrimination in the workplace, including the provision of insurance and health care.²¹

The gay community has been surprisingly successful in many of these spheres due to its own organizational sophistication as well as to the efforts of non-gays moved by appeals to social equity and justice. But it is not clear that the lesbian and gay community and, even less, any of the other affected groups, has the resources to continue to fight forever on so many fronts while large numbers of its members are ill and dying. Nor should it have to: it requires and deserves the assistance of the rest of American society in its struggle.

20. Bigel Institute for Health Policy and United Hospital Fund of New York, *New York City's Hospital Occupancy Crisis*, (New York: United Hospital Fund, March, 1988); D.P. ANDRULIS, *CRISIS AT THE FRONTLINE* 50 (1989).

21. The information in this section is based on personal communications from David Hansell, chief legal counsel at Gay Men's Health Crisis and Wayne Kawadler, coordinator, Insurance Committee of New York's ACT-UP.

V.

It is clear that the American health-care financing system, centered around private health insurance, has not served the struggle against AIDS well. It has, in fact, placed additional burdens on both individuals and groups rather than contributing to an easing of the already serious problems caused by the epidemic itself. The system's inability to constitute a true "insurance community" out of the disparate groups that make up our society has contributed to the further collapse of a sense of community in American society, a sense already rendered fragile by the emergence of AIDS.

In most respects, of course, AIDS is not unique in demonstrating the serious flaws of our current health care financing system. However, the peculiar nature of the syndrome, in particular its unusual relationship to date with specific groups and regions, provides us with a kind of prism in which to view those problems all the more clearly. Most significantly, AIDS demonstrates the contradiction inherent in meeting a basic social need through a private insurance system whose nature and internal development is determined by profitability and cost issues, narrowly construed as the interests of insurance companies and employers rather than those of society as a whole. The most striking aspect of this contradiction is surely the obvious need of the system to build in socially undesirable discrimination by excluding, as far as it is within its power to do so, precisely those most in need of health care. Such a system can scarcely be expected to serve as an efficient mechanism for the inclusion of the entire community of Americans within an equitable system of access to necessary health care.

A significant portion of the problems of the system derive directly from its basis in employment. Placing employer-provided insurance at the heart of health care financing has had the effect of vitiating universality and uniformity of coverage. It has led to the narrowing of the risk pools within which the costs of health care are spread, so that the burdens of health care cannot be shared by the entire society, but are disproportionately placed on the backs of particular individuals and groups, depending on their accidental experiences and needs. Finally, it places in the hands of employers and insurers an unusual degree of power to decide issues of fundamental importance to society as a whole, among them who and what will be covered and how and at what levels reimbursement will be made.

Governmental entitlement programs were created in the 1960s in an attempt to provide health coverage to those who were most obviously left out of the employer-centered private insurance system. These programs, in turn, have failed to achieve the equity and universality that could not be achieved in the central mechanism of the health care financing system. In part, this has been due to the unwillingness or inability of government at all levels to provide the full funding necessary for such programs. In part, also, it has been due to the fact that the risk pools constructed by government programs, large as they are, have still not been large enough to spread costs and reduce them on an average basis, since, by their very nature, they inevitably attract a large proportion of the heaviest utilizers of health care.

If we are to rectify these flaws, and solve the major problems of health care financing that exist for persons with AIDS and other major diseases, our health care financing system must be reconstructed using a different set of principles. The restoration of community, it seems to us and to increasingly large numbers of other observers, can be achieved only through a system that offers universal and uniform coverage to all Americans, regardless of location within the employment system or familial relationship to other citizens.

The most obvious and, at least conceptually, simple approach to such a system is some version of government-sponsored and provided national health insurance, which would replace the current system entirely. In what appears to be the absence of a viable movement to create a national health insurance system at present, we will, however, almost certainly have to accept something less than a thoroughgoing replacement of the current system, at least in the near term.

A less dramatic, but still largely acceptable approach would build on the strengths of the present system and attempt to mitigate its weaknesses. Such an approach is unlikely to be successful unless it involves the participation of insurers and employers as well as government at all levels, with government leading the way through sweeping legislative and regulatory initiatives. Some promising proposals have already appeared, including the "Basic Health Benefits for All Americans" bill of Senator Kennedy²² and Representative Waxman²³ and the recommendations of the so-called Pepper Commission,²⁴ at the

22. S. 768, 101st Cong., 1st Sess. (1989).

23. H.R. 1845, 101st Cong., 1st Sess. (1989).

24. U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE,

federal level, and a number of similar initiatives at the state, local, and private levels. The best of these proposals are based on a set of interconnected elements:

1. Mandated employer-provided insurance, with all employees and dependents provided with at least a minimum package of benefits and with limited patient co-payments and premium responsibilities.
2. An altered insurance underwriting environment, at least for smaller groups and individual purchasers, that recreates some version of community rating through mandated open enrollment, acceptance of all who apply, uniform premiums for identical coverage (without adjustment for age, gender, or industry), and the like.
3. Expansion of Medicaid to at least the federally-defined poverty level, with either new government programs covering those not entitled to private insurance or direct subsidies to them for its purchase.

Initiatives using these elements, even if they do not create a theoretically ideal health care financing system, should eliminate many of the worst flaws of the current system and go far toward creating universal, uniform, and equitable health coverage and access to health care. They will at the very least eliminate many of the most serious problems for persons with AIDS and those most at risk for it as well as for all others with serious illnesses.

Proposals to reform the health care financing system that do not incorporate at least some version of the elements discussed here are inevitably doomed to failure, since they will founder on the fundamental flaws of the current system. For example, proposals to create a network of state-sponsored insurance pools for otherwise uninsurable persons or specifically for persons with particular conditions, such as AIDS, continue to surface from time to time, in particular from within the insurance industry. Such systems are seen as means of widening the pools on which insurance is based and subsidizing them using outside funds (general public revenues or levies on existing private insurance).

Nineteen state pools of this type are already in operation or will be operational in the near future, and their experience is not encouraging. With the exception of Minnesota (with a total of about 14,000 participants), none of the existing pools has

achieved more than a few thousand participants, premiums remain quite high, and the losses that must be made up from outside sources are significant.²⁵ It is obvious that state pools do little to alleviate, and in fact exacerbate, the problem of narrow risk pools, attracting, as they do by their very nature and design, only the least healthy portion of the population.

The widest possible reforms of the health care financing system are therefore required. In order to ensure that initiatives that fall short of a complete government-sponsored national health insurance system work most efficiently, it will be necessary, in the particular case of AIDS, to combine them with other proposals that deal, directly or indirectly, with the more general crisis of community inclusion and exclusion touched off by the epidemic. Most importantly, to ensure that gay people and persons with AIDS are no longer left out of the wider society requires a struggle against both homophobia and "AIDS-phobia," ideally led by the political and moral leaders of our society, who have, in the past, too often remained silent or been hostile. Necessary first steps on this front are the passage of federal and state legislation banning discrimination against persons with AIDS and other disabilities as well as discrimination against lesbians and gay men. Legislation of this type will prevent those who have borne the burden of AIDS for the last ten years from being further marginalized both in society in general and in those areas of employment and insurance most relevant to the provision of necessary health care.

Finally, AIDS has, as we have noted briefly, created intolerable burdens for particular regions or cities, burdens which have scarcely been shared by the nation as a whole. This aspect of the breakdown of the wider sense of community can be addressed not only by changes in our health financing system but by legislation of the type introduced into Congress by Senator Kennedy and others ("CARE: the Comprehensive AIDS Resource Emergency Act of 1990"), which will specifically provide millions of dollars to New York, San Francisco, Los Angeles and other cities with a disproportionate number of persons with AIDS.²⁶

Initiatives of the sort recommended here, that deal with the crises of community in both senses in which we have used

25. On state risk pools, the states that have instituted them, the level of participation in them, and their numerous financial problems, see McEachern, *Problem of Uninsured Spurs More States to Consider Risk Pools, Employer Mandates*, 2 *MANAGED HEALTH CARE* (1990).

26. See *Kennedy Bill to Help Hospitals That are Burdened by AIDS*, NATION'S HEALTH, Apr. 1990, at 4.

the term in this essay, will be necessary if we are to be able to deal with AIDS and other serious illnesses effectively, equitably, and compassionately. If we remain unwilling to make these changes, the reality of community will continue to erode in America, with massive inequities and injustice the rule not only for gays, IV drug users, and persons with AIDS, but for all-too-many of our citizens.

