The ability of people with HIV infection to acquire health insurance varies tremendously from state to state, from jurisdiction to jurisdiction within states, and from job to job within the workplace. In far too many situations, insurance is either completely unavailable or prohibitively expensive. When it is available, it often includes draconian limitations on pre-existing conditions and important benefits like prescription drugs, mental health care, home care or hospice.

President Clinton's Health Security Act makes significant progress in dealing with most of these problems. Most importantly, it would eliminate all pre-existing condition exclusions: no one could be denied insurance, or charged a higher premium, because they had any illness prior to coverage. It would also eliminate lifetime maximums, which in recent years have affected hemophiliacs with HIV disease who must spend up to $15,000 every two months for blood products, and would cover prescription drugs and mental health services.

The plan is not perfect. Some critics say it does not go far enough in reforming the current confusion of public and private programs with different eligibility criterion, widely varying benefit packages, and exclusionary rate structures. Others say it goes too far—raising the battle cry of “socialized medicine.” Between the two extremes are a large number of people who believe the Health Security Act is a thoughtful, comprehensive, and equitable effort to extend health care coverage to all Americans.

For the vast majority of people with HIV disease who have private insurance, the comprehensive benefits package in the Health Security Act would be comparable to—or richer than—the benefits they have now. For those receiving coverage under Medicaid or other public programs, the package would be a significant improvement. And for those with no coverage at all, the plan eliminates a major source of stress and anxiety in their lives, ensures adequate treatment, and protects against financial ruin.

The Rationale and Motivation for Reform

While some public figures assert that there is no crisis in health care, the White House Health Care Task Force did not hear from an “ordinary” American who did not have a health care horror story about him or herself, or his or her family or close friends. In conversations with people with HIV disease and AIDS, the stories have been even more pronounced. It is the statistics behind health care reform, however, that recount the most compelling story of all.

First, for people without private health insurance across the country, there are terrible discrepancies in terms of access to care and services available, and 100,000 Americans move into the ranks of the uninsured each month. These inequities are exacerbated for people with HIV disease. According to the National Commission on AIDS, in 1991, 40 percent of people with AIDS were covered by Medicaid and 29 percent had incomes too high to qualify for Medicaid, but nonetheless could not get or afford private insurance.

State Medicaid programs themselves are notoriously inaccessible. Patients must “spend down” and divest themselves of resources in order to become eligible for benefits. Forms are often so confusing to fill out that many public hospitals have hired full-time staff to decipher them. Patients can wait months for initial appointments at clinics that accept Medicaid, and because of lower reimbursement rates and delayed payments, many health
Editorial: Health Care Mythology
Robert Marks, Editor

It’s hard to imagine that there is anything left to say about health care reform, anything that has not already been reported in the media blitz surrounding President Clinton’s Health Security Act. But the media has not covered clearly the implications of reform for HIV-related care. Nor, in its focus on the economics of managed care, has it dealt with philosophical issues related to managing health.

This issue of FOCUS brings together two health care policy wonks who have looked at this issue from their different perspectives: one from the inside—sitting on the president’s health care reform advisory task force—and the other from the outside—watching the proposals unfold from the leading AIDS policy advocacy organization in the country. These two views come to similar conclusions: health care reform at its best will improve HIV-related care; at its worst, it could sacrifice crucial services funded under existing HIV-related legislation. Of particular concern, most proposals limit mental health care and substance abuse treatment—but perhaps not any more than they are under typical health insurance plans.

It is this limitation that raises questions that have not been sufficiently addressed in the health care reform debate. There has been little public discussion about the American conception of health and the role of health care. In a fascinating article, which we abstract in this issue’s Recent Report section, William Gaylin, a Columbia University psychiatrist, raises these issues. Among his conclusions, he states that we have become victims of health care that is too effective—that medical knowledge and technology keep us alive after we would have “normally” died, that is, with our health intact and requiring expensive maintenance.

In a society where fitness and good health are idolized, is it ironic that health care is only glibly acknowledged as a governmental responsibility? Is it ironic that many of the health care providers will not accept Medicaid patients.

Second, these problems are not exclusive to the poor. More than half of the uninsured in 1990 were full-time workers and their families, and more than one million of those who lost health insurance in 1992 were earning between $25,000 and $49,000 per year. One out of every three Americans earning between $30,000 and $50,000 annually report that members of their household have stayed in jobs they wanted to leave because they were afraid of losing health care coverage. There appears to be a tragic corollary to this statistic: many people with HIV disease actually fear losing their jobs and insurance more than they fear losing their lives, in large part because they do not want to become a financial burden to family, friends, or society.

Finally, in just 25 years time the percent of the U.S. Gross National Product (GNP) consumed by health care expenditures more than doubled, from 6 percent to 12 percent, and the actual numbers soared from $42 billion to $666 billion. Health care expenditures increased at more than twice the rate of GNP growth. This accumulation of staggering economic and personal costs has brought about a rare moment in the life of this nation: a moral imperative—the need to care for one another—has also become a political and economic imperative.

Benefits of the Health Security Act

There are many elements of the Health Security Act that have positive implications for people with HIV disease. The following points highlight those changes that will have the most immediate or substantive benefits in four areas: extent of coverage, types of services, and systemic efficiency, and mental health and substance abuse coverage.
Extent of Coverage. First, the plan would end “medical underwriting,” eliminating “pre-existing condition” exclusions and waiting periods for anyone, regardless of health status. Second, insurers would no longer assess premiums based on individual demographics or health characteristics. Instead, factors that currently increase costs to individuals—such as age and pre-existing conditions—would be spread across whole communities. Finally, the plan would eliminate lifetime maximums. No one would need worry that an expensive medicine or course of treatment would raise costs to an arbitrary “ceiling” and lead to an end to their coverage for all other services.

Types of Services. The plan would include home- and community-based alternatives to hospitalization as an integral part of the health care reform package. It would recognize and cover preventive intervention, programs and services that seek to keep people well and prevent the onset of serious HIV-related diseases.

Perhaps most importantly for people with HIV disease, it would make prescription drugs affordable. For too many people and families struggling with HIV disease, drugs are the largest cost of daily living, forcing people to choose between buying food and paying for medication. In addition, for people with AIDS on Medicaid, prescription drug benefits vary widely from state to state. In some states, AIDS drug assistance programs (ADAP) cover zidovudine (ZDV; AZT) and its analogs and nothing else; in others, like New York, ADAP covers all drugs and some nutritional supplements.

Systemic Efficiency. The proposal would level the tremendous regional disparities in public programs, that is, Medicaid and state-only plans, minimizing the need for people with HIV disease to migrate to other places for adequate health care coverage. Over time, as HIV-related expertise grows more routinely available, people with HIV disease living in urban areas could move back to their families of origin without worrying about variations in treatment capability and covered benefits, which would be uniform throughout the country. It would also streamline the process by standardizing forms and reducing the micromanagement of care delivery by health care “gatekeepers,” people who may never have been near the front lines of health care delivery.

Mental Health and Substance Abuse Coverage. The plan would offer limited mental health and substance abuse benefits, and mental health benefits would achieve full parity with physical health benefits after 2001. The plan would cover services by mental health providers including psychiatrists, psychologists, and licensed social workers. The initial plan would closely resemble most private plans today, for example, 30 mental health visits per year with either a $10 or 20 percent copayment (psychotherapy would initially have a $25 per visit or 50 percent copayment), and 30 days per year of inpatient treatment. The copayments associated with these services, however, would not count in the annual out-of-pocket maximums of $1,500 for individuals or $3,000 for families. Since most state Medicaid programs do not cover mental health services, for the 70 percent of people with AIDS who have no insurance or who rely on Medicaid, even this initial benefit would represent a significant improvement.

Conclusion

The primary alternatives to the Health Security Act include the Cooper-Grandy, McDermott-Wellstone, and Chafee-Dole plans. Cooper-Grandy is currently receiving a great deal of media attention, but while the proposal would offer universal access to coverage, it would not guarantee the financial means to pay for it. McDermott-Wellstone is a single-payer plan with numerous proponents, but, because the federal government would become the insurer and the entire private insurance industry would be eliminated, the plan is not thought to be viable. The Chafee-Dole plan would substitute an individual mandate for the employer mandate, that is, all individuals would have to purchase insurance, but employers would not be required to provide it.

For the first time in decades—and probably in the current session of Congress—it is very likely that a hybrid of these plans will result in meaningful reform of the financing and delivery of health care in this nation. The Health Security Act includes many proposals that offer improvements in coverage and financial relief for people with HIV disease and all other long-term chronic, disabling—and expensive—diseases.

In his State of the Union address, the President emphasized the fundamentals of reform: every American must be covered and the coverage must always be there. For the HIV-affected community, no two benefits could be more important.
People with chronic diseases like HIV infection demand the most from our health care system and, in its present form, often get the least. Currently, 40 percent of people with AIDS are on Medicaid and another 29 percent are uninsured, and those with private health insurance often have limited benefits or high out-of-pocket costs. This inability to access care diminishes the length and quality of life for people with HIV disease. While it is clear that some kind of health care reform will be approved in 1994, how well the final reform plan addresses these realities will be the true measure of its value.

The Health Security Act

President Clinton’s Health Security Act proposes to guarantee health insurance coverage with a standard set of comprehensive benefits for all legal residents of the United States. The act would provide insurance through regional alliances that would oversee the purchase and administration of health insurance plans for all residents of a geographic area. It would require all employers to offer their employees health insurance, paying, on average, 80 percent of the premium for full-time employees. The self-employed and unemployed would also be required to purchase health insurance through the regional alliances, with their premiums subsidized or covered by Medicaid if they are poor.

All plans offered under a regional alliance would have to provide the same package of basic benefits, which are fairly comprehensive in covering primary care needs. While everyone would be required to pay something for their care—in the form of fixed copayments or a percentage of fees—different plans could offer different options for accessing care, for example, closed network managed care versus fee-for-service options, although these options would be more expensive. The act would limit premium increases for all types of plan to the rate of health care inflation, and hold individual out-of-pocket costs to about $1,500 a year.

Strengths and Weaknesses of the Act

One way of measuring the strengths and weaknesses of the Clinton proposal is to examine it in terms of some basic principles that should inform any reformed health care system: universality, comprehensiveness, choice, affordability, and government responsibility. Unless these principles are addressed, people with HIV disease will not benefit from health care reform.

Universal Coverage. The Clinton proposal would assure all U.S. citizens and legal residents coverage by January 1, 1998. It would not cover undocumented immigrants and incarcerated inmates, leaving these two populations with high rates of HIV disease to receive care only through the existing public health safety net. For those who are covered, there would be important protections: all plans would have the same minimum benefits package, would eliminate pre-existing condition clauses, would determine premiums by community rating, and would be free from ceilings on coverage for any specific disease. Community rating, whereby everyone pays the same premium regardless of health status, is particularly crucial for making insurance accessible for people with chronic diseases.

Comprehensiveness. The Clinton proposal would cover all medically necessary services, including the full range of benefits normally associated with a good private health insurance plan, that is, most inpatient and outpatient services. In addi-
tion, the plan emphasizes coverage of clinical preventive services, including screening for cervical and breast cancer, HIV antibody testing, and immunizations. The plan also covers, among other things, limited substance abuse and mental health treatment, hospice care, and 60 days of home health care as an alternative to hospitalization. Additions or changes to this minimum package could be made by Congress or by the National Health Board, created to oversee the entire new system.

Unfortunately, the combined substance abuse and mental health benefit has severe limitations on usage. For example, each time a person accesses mental health services, his or her substance abuse benefit would diminish accordingly, and vice versa. Not until 2001 would substance abuse and mental health services achieve the same level of coverage as other health benefits. Within limits, the Clinton proposal would cover inpatient and residential mental illness and substance abuse treatment; intensive nonresidential mental illness and substance abuse treatment; outpatient mental illness and substance abuse treatment, including case management, screening, and assessment; crisis services; and collateral supportive services.

The combined benefit would be limited to a total of 30 days per year of residential or inpatient treatment, with the possibility of a 30-day extension, and 60 days of outpatient treatment. Each day of residential or inpatient treatment could be swapped for two days of intensive nonresidential treatment or three days (visits) of outpatient counseling. The mental health benefit would also require significant copayments.

These severe limitations impose obstacles for people with HIV disease or at risk for HIV infection, who are likely to need to address underlying substance abuse issues as well as mental health issues associated with having HIV disease. This proposal would make it almost impossible to get effective substance abuse treatment and adequate mental health services. Even if substance abuse treatment were the only part of the benefit accessed, care would be insufficient.

Access to experimental treatments and off-label uses of approved treatments is critical to the care of people with HIV disease. The Clinton proposal would, in general, assure access to off-label indications (licensed drugs prescribed for new uses), but individual plans would have the discretion to impose some restrictions. The act would also assure coverage of participants in clinical trials; the extent of coverage of experimental treatments outside trials, however, would be left up to individual health plans. The act does not cover alternative therapies such as acupuncture, chiropractic care, or homeopathy.

Freedom of Choice. The Clinton proposal assures that everyone would have more than one plan to choose from, not often the case for those getting insurance through their employers. However, the proposal would depend upon the managed care approach to hold down costs, and fee-for-service or flexible network plans would incur higher copayments and premiums. Those on Medicaid would not be subsidized for these more expensive plans. Choice is therefore dependent on ability to pay.


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See also references cited in articles in this issue.
This is particularly troublesome for people with HIV disease. The kind of expertise HIV-related care requires may not be available in every plan, especially for those in smaller communities. The higher cost sharing associated with fee-for-service plans, however, may make it prohibitive for people with HIV disease and impossible for people on Medicaid.

Two elements of the Clinton proposal would mitigate this situation to some extent. The proposal would require all plans to have arrangements with academic health centers to provide expert care for diseases like HIV infection, and treatment at these centers would not cost more. Similarly, each plan would have arrangements with so-called “essential” community providers, those existing health clinics—including Ryan White CARE Act providers—that specialize in caring for underserved populations.

Affordability. The Clinton proposal assumes some predictability in costs: premiums could rise only with the rate of health care inflation, out-of-pocket expenses beyond premiums would be capped at $1,500, no individual would have to pay more than 3.9 percent of his or her income in premiums, subsidies would be provided for those with incomes below 150 percent of poverty but not on Medicaid, and Medicaid would cover the premiums of people on Medicaid cash assistance.* These are important improvements, but people with chronic diseases may still face special challenges, for example, coming up with $1,500 in one lump sum and early in a year. In addition, more flexible subsidies—beyond 150 percent of poverty—would help people who would not meet the proposal’s criteria for “poverty.”

Government Responsibility. The Clinton Administration is committed to having the government exercise greater authority over health care, from limiting costs, to regulating how insurance is underwritten, to assuring that underserved communities have sufficient providers. Importantly, the Clinton proposal also recognizes that this more centralized system—complete with health security cards—would require vigilant attention to confidentiality and discrimination. Unfortunately, much of the confidentiality protections for the proposal are to be written in the future, and, of those that have been defined, some would not go far enough. For example, the proposal would ban discrimination in providing services based on health status, but would lack protection against sexual orientation discrimination and would include no recognition of alternative family arrangements. Finally, the Clinton proposal retains the existing public health infrastructure (including the Ryan White CARE Act program), while expanding, within the plan and through new initiatives, a commitment to prevention.

Conclusion

This summary of a complex plan—some would argue too complex for its own political good—shows that the Clinton Administration has moved forward in critical directions for people with HIV disease. The proposal would achieve relatively universal coverage, clear predictability of cost for the individual, reasonably comprehensive coverage, and assistance to the poor in accessing these services.

While it is hard to predict the ultimate outcome of the proposal, three things are clear. Congress will pass some legislation this year and call it health care reform. The final product will look significantly different from the original Clinton plan. There is strong pressure to leave the system alone, undertaking only minor reforms that rely on the marketplace to assure access.

It is impossible to know what approach will finally prevail, but it is clear that people with HIV disease will be the losers if the resulting legislation does not incorporate fundamental change. AIDS advocates need to join with the Clinton administration to assure that the final plan offers: universality of coverage through the employer mandate, a comprehensive benefits package guaranteed by law, community rating that spreads the risk of illness among all Americans and makes insurance affordable for people with HIV disease, and the previously instituted HIV-related safety net created by programs such as the Ryan White CARE Act.

Authors
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Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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*For a family of four, 150 percent of poverty is $21,500; for an individual, it is $10,800.
**Recent Reports**

**Privacy and Health Care Reform**  

Policy makers are trying to balance appropriate privacy and autonomy with the requirements of an efficient health care system and an adequate and reliable informational basis for health care planning, according to a commentary on confidentiality and health care reform.

Currently, privacy and confidentiality protections are a product of federal and state constitutional law and statutes, and state common law—"a morass of erratic law." Due to the absence of uniform privacy and confidentiality protection, continued reliance on current legal safeguards is incompatible with the policy objective of an integrated national health care system. State-by-state regulations, for example, ignore the fact that the flow of medical information is rarely restricted to the state in which it is generated. Further, state protections become futile at a time when the physical location of health information is no longer relevant, when databases with huge amounts of health information provide immediate access by a variety of eligible users in remote locations.

In response, the federal government should first establish national privacy safeguards based on a code of fair information practices, including: the individual right to know about and approve uses of data; the prohibition of secret data systems; and the individual right to review and correct data.

Second, the government must establish a universal identifier that will provide more privacy protection than a social security number, the most common identifier.* Third, the government should develop standards to ensure the security of automated information systems.

Fourth, the government should empower a data protection and security panel. Its responsibilities would include: setting and monitoring privacy and security standards; establishing mechanisms through which individuals could question the propriety of the collection and use of information; and supporting the development of a fair and comprehensible disclosure consent process.

Finally, the government must develop a comprehensive education program to teach health care professionals about their rights and responsibilities regarding privacy and security of information.

**Access, Egress, and Allocation**  

The health care reform debate has misdiagnosed the economic ills plaguing the system and has failed to address central philosophical issues, according to an essay on rationing health care. "Efficiency experts" have taken control of the debate, erroneously assuming that eliminating waste will obviate the need for rationing. Further, by ignoring societal attitudes toward life and death, the goals of medicine, the meaning of "health," suffering versus survival, and who shall live and who shall die, planners have lost the opportunity to reach democratic consensus about rationing.

Health care costs are driven by four factors: the increase in health problems due to good medicine that enables people in poor health to live longer; the expanding concept of health; the seduction by technology of both doctor and patient; and the "American character," which seeks to solve things completely and immediately. Given these factors, there are three ways to contain health care spending: limit access (who gets care), egress (for how long) and allocation (what can be provided).

Access to scarce and expensive resources must be organized on some equitable basis—even if equitable does not mean full coverage for everybody and everything. Various factors might be considered to determine who should receive what, most prominently, age: all things being equal, most would agree a 16-year-old boy has a greater claim on an organ than a 72-year-old man.

Even more complex than deciding who deserves access, is when, and if, access should end. For example, how long should one patient have an artificial heart while others are waiting? New medical technology has become so ingrained that once lifesaving technology is introduced, we tend

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*Universal identifiers are unique numbers, or number and letter combinations, used to track individuals as they use a system’s resources.*
to consider it a right, not a privilege. Perhaps we need to think more seriously to begin with about what sort of technologies we want to develop. But how can we limit scientific inquiry? We can’t—but we can debate what we as a society are willing to fund, just as we now debate whether we really need a supercollider.

The central issue of allocation is coming to terms with the fact that no matter how efficient or economical we make health care, we will never be able to do everything for everyone. Choices among competing health needs, sometimes tragic, are moral and ethical, not medical. They are best made through the democratic process by all of us—as was accomplished in Oregon—rather than through the current health care reform process, which is being conducted behind closed doors.

Privatized Mental Health Care


Massachusetts state officials are privatizing mental health care in response to pressures to provide better care at lower cost. According to an overview of this experiment, which includes a detailed history of mental health care in the United States, the plan aims toward achieving the ideal of efficient and effective community care by closing outmoded state hospitals and transferring patients into privately owned and operated community-based alternatives.

The foundation for this change was laid by the 1986 Brewster decree. The decree ordered the creation of three components: new residences and acute care beds in private general hospitals to provide former state hospital patients care in their own communities; treatment, training, and support programs to ensure clients transferred into the community continued to function successfully; and management services to develop, coordinate, administer, monitor, and evaluate the network of community programs.

By harnessing marketplace competition to encourage cost savings and quality, privatization uses resources in new ways to achieve higher quality and greater efficiency. It frees the government from providing care and enables it to concentrate on quality control. Its foundation—that patients are happier and more effectively treated in community versus institutional settings—is borne out by the Massachusetts experiment.

The Massachusetts plan improves the quality of short-term institutional care by creating more psychiatric beds in private general hospitals. This eliminates an historical inequity that relegated uninsured patients to remote state institutions while treating insured patients in community hospitals.

The peril of privatization is that “revolving door” patients—mentally ill patients who, functional at release, stop taking their medications and must be readmitted to hospitals again and again—may fall through the cracks of community care. Even more troublesome, is that under a privatized system, the quantity of acute short-term care beds is strictly limited, and providers may find themselves under pressure to release people not “dangerous enough” to meet commitment standards, but still in need of short-term care.

While these dilemmas are significant, privatization’s promise can be achieved if the plan has sufficient staff support, programs, and services. To avoid a breakdown of the system, virtually all savings generated from transferring mental health care into private hands must be rededicated to the programs that keep patients functioning in the community.

Next Month

The National Association of Social Workers made news last summer when they became the first of the counseling professional organizations to put into its code of conduct ethical guidelines for attending the assisted suicides of clients. In the April issue of FOCUS, Jerome A. Motto, MD, an internationally recognized expert on suicide and Professor Emeritus of Psychiatry at the University of California San Francisco, discusses rational suicide in the context of clinical practice. He briefly recounts the recent history of rational suicide and explores the clinical approach to clients who wish to pursue this option.

Last spring, Compassion in Dying was founded in Seattle to facilitate physician-assisted suicide. Also in the April issue, Susan J. Dunshee, President of the Board of Compassion and Executive Director of the Seattle AIDS Support Group, writes about the organization’s experience counseling terminally-ill people and their loved ones about suicide.
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